

**A CASE STUDY EXPLORING DISABILITY INCLUSION WITHIN THE
MUSLIM UMMAH IN SOUTH AFRICA**

by

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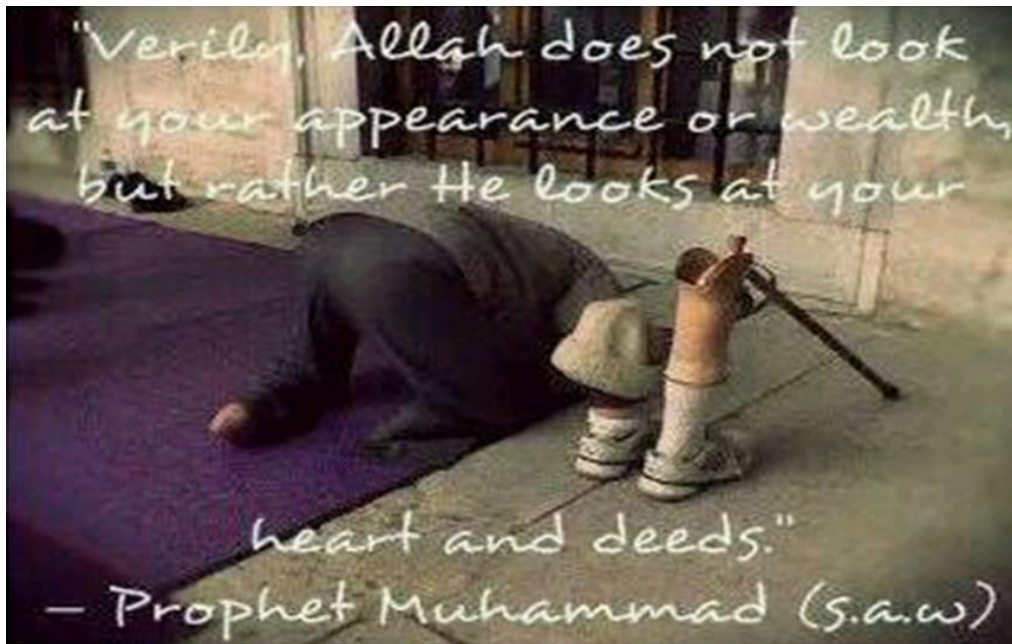
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DECLARATION

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Nafisa Mayat

DEDICATED TO MY PARENTS



As reflected by the quotation above, God the Most High, looks not towards His slaves and their bodies, whether they are large or small in stature or whether they are in a state of good health or sickness. He does not look at their faces and question whether they are beautiful or disfigured. All these matters are of no significance before God. Similarly, He does not consider ancestry, whether or not they are of noble or ignoble parentage; neither does He look towards their wealth.

This narration directs us towards the principle established in the Holy Quran, (Shafi, 2004, pp. 143-144) "Oh mankind! We have created you from a [single] male and female, and made you into nations and tribes, in order that you may become acquainted with one another. Verily the most noble amongst you before God are those who are greater in Piety (God-Fearing)".

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ABSTRACT

Religion and spirituality are central to the way many people, including persons with disabilities, make sense of both the world itself, and their place in that world. However, in most scholarship focusing on disability, religion, as a way of understanding and dealing with disability, is side-lined or absent (Imhoff, 2017). Islam has a long rich history in South Africa and is currently one of the major religions here (Mahida, 2012). Followers of Islam are commonly referred to as members of the Muslim Ummah as a collective, an Ummah that includes persons with disabilities and non-disabled persons. Given the paucity of research focusing on disability in the Muslim Ummah in South Africa, this study sets out to gain insight into the way disability inclusion is enacted within the Muslim Ummah in South Africa.

The research question asks: How is disability inclusion interpreted, experienced and enacted by people within the Muslim Ummah in South Africa?

Adopting an interpretative qualitative research approach and applying an intrinsic case study method, the research was conducted with members of the Ummah in three major cities in South Africa, viz. Durban, Johannesburg and Cape Town. Data was generated from persons with disabilities, family members of persons with disabilities, the Ulema and a non-disabled person from the Ummah from each city. In-depth face-to-face interviews and a review of three Muslim publications were used as data gathering mechanisms. Interviews were held with seven persons with disabilities, either a physical or sensory disability, five family members of participants with disabilities, six Ulema and three non-disabled persons. All participants were aged 18 and older.

Data was analysed by looking for themes that emerged from the data. Three themes, “Seen as Inferior”, “Carrying the Weight for Inclusion” and “We Are Not Doing Enough”, each with two sub-themes, emerged from the analysis. “Seen as Inferior” and its two sub- themes, “Gaze of Othering and “The Deep Impact of Disability”, highlight the way in which persons with disabilities are viewed as inferior within the Ummah and how this is reflected in the gaze of non-disabled persons on persons with disabilities and their families, and the impact of this gaze.

“Carrying the Weight For Inclusion” emphasises the responsibility that persons with disabilities have assumed in order to be accepted into and included in the Ummah and this is demonstrated through the two sub-themes, “The Unspoken Responsibility of Negotiating Persons with Disabilities” and “Negotiating the Effort to be at the Masjid”.

“We Are Not Doing Enough” explains that although some aspects of inclusion are evident within the Muslim Ummah, the pace of change is very slow and inclusion remains inadequate. Sub-themes “Inclusion could Create Ease and Belonging” and “Still a Journey to Travel to be Included” capture the way disability inclusion is interpreted and experienced by the participants of the study, highlighting that much work is still needed to attain full inclusion and to create ease and belonging for persons with disabilities within the Ummah.

The discussion explains how the dominant discourse around disability is one that reflects an ableist, normative, colonial narrative. This narrative influences how disability inclusion is enacted within the Ummah, belabouring a move to full inclusion. The phenomenon of an unconscious exclusion of persons with disabilities within the Ummah is discussed as it emerges from this dominant discourse, together with the silence that sustains the continuation of the exclusion. The ways in which this unconscious exclusion plays out in many spaces and places significant to the lives of persons with disabilities are identified. It is proposed that, in order to achieve full inclusion and belonging for persons with disabilities within the Ummah, there needs to be a re-shaping in the thinking around disability through generating new knowledge and by challenging the dominance of the normative, ableist narrative. Informed by a decolonial turn, pathways towards full inclusion and belonging of persons with disabilities within the Ummah are proposed. It is suggested that collective action by both persons with disabilities and non-disabled persons within the Ummah is needed for full inclusion and belonging to transpire. The pathway to full inclusion and belonging would enable systemic change around disability within the Ummah to ensue and it would help move the de-colonisation project forward.

DEFINITION OF TERMS

ADHAAN: Islamic call to prayer

ALLAH: The Supreme Being, God

ASR SALAAH: Late afternoon prayer

DEEN: An Arabic word which refers to the way of life Muslims adopt to comply with divine law, encompassing beliefs, character and deeds.

DEAF: -Deaf **with a capital D** is used for people who use sign language and identify as part of the Deaf culture

Deaf: deaf **with a lower-case d**, is used to refer to individuals who are hearing impaired

DISABILITY INCLUSION: Disability Inclusion refers to the full inclusion of persons with disabilities within all spheres of society, having access to opportunities that enable them to play their role of choice within the networks to which they belong and where they give and receive support. This translates to full inclusion and belonging within the Ummah (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Rimmerman, 2013).

DISABILITY: The United Convention on the Rights of Persons with Disabilities (UNCRPD), states that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others” (UNCRPD: 4).

FAMILY: – A group consisting of one or more parents and their children

HADITH: The traditions of the Prophet (Peace and Blessings be Upon him) i.e. his sayings and deeds

HIFZ –Learning to memorise the Quran

IMAM: The person who leads the prayer in a Mosque

ISLAM: The Muslim religion, based on the belief in one God, revealed through Muhammad as the Prophet of Allah

KUTBAH: An occasion of public speaking in the Islamic tradition. An example is the sermon during Friday noon prayers

MADRASAH: A Muslim school

MASJID: A Mosque. Any Masjid where the practices are devoted absolutely to the God Alone. A place of prayer (Arabic meaning of mosque)

MAGHRIB SALAAH: Early evening prayer

MIMBAR: A short flight of steps used as a platform by a preacher in a Mosque

MOULANA: A Muslim Priest

MUSALLIES: Congregants at the mosque

MUSLIM: A follower of the religion of Islam

MUSSALA: - A prayer place or a prayer mat

MUTAWALLI: A Trustee of the mosque

NAMAAZ: Islamic worship or prayer (similar to Salaah)

NON-DISABLED PERSON: Persons who do not have any long-term physical, mental, intellectual or sensory impairment and who do not encounter barriers that might hinder their full and effective participation in society on an equal basis with others

PERSON WITH A DISABILITY: Persons who have a long-term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (UNCRPD, 2006)

SALAAH: The practice of formal worship in Islam

SUF: Rows of people standing during prayer

ULEMA: -Group of Islamic theologians

UMMAH: An Arabic word describing a people or a community

WUDHU: Ablution before prayer

ACRONYMS

CA: Capability Approach

ICF: International Classification of Functioning, Disability and Health

ICIDH: International Classification of Impairment and Handicap

PBUH: Peace and Blessings Be Upon Him

NCRPD: United Nations Convention on the Rights of Persons with Disabilities

WHO: World Health Organisation

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CHAPTER ONE: INTRODUCTION

Chapter one introduces this study which focuses on disability inclusion in the Muslim Ummah. The chapter begins by providing the background to the study, outlining the concepts of disability inclusion and the Muslim Ummah. The evolution of the study is then described, starting with describing how the researcher ‘tested the waters’ as part of the process of shaping the research question and specific objectives. The purpose of the study is presented and is followed by an outline of each of the chapters.

1.1 BACKGROUND

The World Health Organisation (WHO) estimates that there are approximately 1 billion people, that is, 15 % of the world’s population with a disability (Groce, 2018). It is further estimated that approximately 10 % of the general African population have a disability (Disabled World, 2020). However, obtaining accurate disability prevalence is often complex because of the various understandings of disability (Amosun, Jelsma, & Maart, 2019). The authors further contend that context and a more nuanced understanding of disability is critical in order to capture accurate disability prevalence.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRDP) advocates for the rights of all persons with disabilities, providing countries with guidelines on how these may be implemented. South Africa, with an approximate disability prevalence of 7.5 % (Statistics South Africa, 2011)¹ has accepted the guidelines of this convention.

The ratification by South Africa places it under an obligation to ensure that matters related to persons with disabilities are on the country’s implementation agenda. To this end, the country has developed relevant policies, as reflected in the Bill of Rights in the Constitution of South Africa, for the provision for access to post-school training and economic opportunities for persons with disabilities (Green Gazette, 2020). However, the implementation of these policies is still a major challenge and consequently, persons with disabilities remain marginalised in South Africa. Evidence indicates that persons with

¹ However, these numbers do not include persons with psychosocial and certain neurological disabilities and children under five years of age. This suggests that the prevalence of disability may be higher (Statistics South Africa, 2011)

disabilities face attitudinal, physical and institutional barriers and intersecting inequalities. This can result in multi-dimensional poverty, exclusion and marginalisation (Rohwerder, 2015). Persons with disabilities are often overlooked and left without equal access to health care and rehabilitation, education and employment. They may be marginalised or excluded from the socioeconomic, religious and political lives of their communities (Groce, 2018). Very often this occurs when communities are not equipped to accommodate persons with disabilities.

1.2 UNDERSTANDING DISABILITY INCLUSION

Social inclusion has been described in various ways by different scholars (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Soldatic, Magee, & Robertson, 2019; Wilson, 2000). While there has been much discussion around what constitutes an inclusive society, there is lack of consensus on a clear definition (McKinney & Amosun, 2020). This lack of consensus renders it difficult to measure the extent to which social inclusion is achieved (Cobigo *et al.*, 2012) for persons with disabilities within mainstream society. Social Inclusion is often associated with the concepts of social equality, human rights and democracy, since it involves persons being a part of and able to exercise their rights within, a society (Wilson, 2000). Soldatic *et al.* (2019) posit that social inclusion, a term that has a wide-ranging meaning, has the potential to inform legislative change and changes in the lives of persons with disabilities (Soldatic *et al.*, 2019). A study on the use of the term social inclusion, from a disability studies' perspective, found it to mean that an individual is accepted and recognised as an individual beyond the limitations of the disability. This means that a person with disability is able to have personal relationships with family, friends and acquaintances, be involved in recreational and social activities, have access to appropriate living accommodation, work and have appropriate formal and informal support (Rimmerman, 2013).

Similarly, Cobigo *et al.* (2012), describe social inclusion as comprising a complex interaction between personal and environmental factors that increases an individual's opportunities to contribute to society (Cobigo *et al.*, 2012). In order to achieve social inclusion, Cobigo *et al.* (2012) posit that certain core principles need to be present: access to public goods and services, the experience of valued and expected social roles of one's choosing based on age,

gender and culture, recognition as a competent individual, being trusted to perform social roles in the community and belonging to a social network within which one receives and contributes support.

In this study, disability inclusion refers to the full inclusion of persons with disabilities within all spheres of society. The definition of disability inclusion thus includes that persons with disabilities have access to opportunities that enable them to play roles of their choice within the social networks to which they belong and where they may give and receive support and where they feel valued (Cobigo *et al.*, 2012; Rimmerman, 2013). Full inclusion and belonging for persons with disabilities, thus goes beyond just participation, just being present and expected to fit in their chosen space but being fully immersed and feeling included.

Religion and spirituality are essential to the way many people, including persons with disabilities, make sense of and find comfort in both the world and their place in that world (Imhoff, 2017). Religious beliefs through scriptures and prayers may provide answers that apply to both this life and the next and offer comfort and support to many (Koenig, 2012). However, the ways in which communities enact their particular traditions, values and beliefs may influence how disability inclusion is experienced (Smith, 2007). Lack of access to and negative attitudes towards persons with disabilities often lead to experiences of exclusion. Given that social exclusion encompasses relationships between individuals and the rest of society and goes beyond the narrow responsibility of the individual (Peruzzi, 2014), it can only be assessed by recognising individuals in relation to institutions and structures that may explicitly or implicitly exclude persons with disabilities (Peruzzi, 2014). Although religion may be seen as the personal experience of an individual, its organisation and synthesis are dependent upon collective attitudes of humans (Omer, 2019). Furthermore, since cultural or religious teachings have come to inform the way people negotiate diversity within their own groups, they are a necessary part of understanding disability inclusion. However, the relationship between disability inclusion and religion has not been adequately explored.

1.3 EVOLUTION OF THE STUDY-A PERSONAL JOURNEY

Ever since qualifying as a Social Worker, 31 years ago, I have worked with and advocated for persons with disabilities across different service sectors. Through these experiences, I became increasingly aware of the many challenges, across the spectrum, faced by persons with disabilities.

Initially, working in the townships and rural areas in the Kwa-Zulu Natal province of South Africa, I witnessed, first-hand, the struggles experienced by persons with disabilities in communities: the lack of basic resources, lack of access to education and the discrimination at all levels. As a social worker providing direct services during the apartheid years, it was always a struggle to access adequate funding and resources to try and level the playing field for persons with disabilities. I often felt very frustrated and disillusioned. However, the consequence was that I became conscientised and committed myself to do all that I could to create disability awareness and to work towards the changes necessary within various sectors. I learnt that most services appeared to be informed by a welfare/charity approach and a medical model of disability.

Next, I moved into higher education to work first, as the Co-ordinator of the Disability Unit at the University of Kwa - Zulu Natal (UKZN) and later, as the Disability Advocacy Co-ordinator at the Disability Unit of the University of Cape Town (UCT). While working at UKZN, I started to study for an MPhil in Disability Studies at the University of Cape Town. This shifted my knowledge further, spurring me to become an even more active and vocal disability advocate. This was also fundamental to my work within the university and in the higher education sector where I was confronted with the challenges faced by students with disabilities. My insights from working with persons with disabilities in communities led me to be more cognisant of the challenges experienced by students with disabilities, especially those students from poorly resourced communities. Understanding these challenges made me resolve to advocate for change to the status quo for students with disabilities, leading me to become an Executive member of the Higher Education Disability Services Association of South Africa (Higher and Further Education Disability Services Association, 2020).

When I first started thinking about doing a PhD, my initial plan was to focus on a topic related to my field of work, which was disability and higher education. Seeing first-hand the challenges experienced by students with disabilities and my commitment to enable change, my mind was firm on this focus of study. I started discussions with my supervisor around the direction the study should take. I started working on a concept note for my supervisor.

My family was aware that I had started discussing my area of focus for my PhD. Every so often, my niece would encourage me to put together a pamphlet or some publication to educate the Muslim community about disability. She had trained as a doctor but her knowledge of disability was minimal, highlighting the gap in the curriculum of medical doctors. She had gained knowledge about disability from my engagements about disability with family members. With her increasing knowledge and awareness of the issues and challenges faced by persons with disabilities, she felt that this knowledge should be shared with the community, in particular the Muslim community. This experience together with discussions with manager, who also had a disability, about the neglect of research on religion and disability encouraged me to pursue a topic relating to disability in my Muslim community. Another defining moment which cemented my resolve to focus on disability in the Muslim community occurred at a social function at a close friend's home. During a casual conversation with a group of Muslim friends, I was asked about the sexual abilities of a mutual friend who had a disability and was a wheelchair user. I was shocked and angered by this question which I assumed stemmed from ignorance about disability and persons with disabilities. In response to my own reaction, I paused to check myself was I focussing on my friend's ignorance or was I formulating an answer that promoted disability awareness. This left me thinking about the extent of disability awareness in the Muslim community and what the experiences were of Muslim persons with disabilities. As a disability advocate, I felt that It was my responsibility to create change. I was reminded of the conversations with my niece and my manager.

Continuing to share my interest in the aforementioned research informally with Muslim friends, students and colleagues with disabilities, I was further encouraged to pursue this line of study. Furthermore this was affirmed by prominent local disability activists recognised for their activism, both nationally and internationally. The emphatic urgency to make the

experiences of Muslims with disabilities public was thus supported by activists who stressed the significance of a study of this nature. As I attempted to mould the research, I consulted a disability advocate, Ashraf (a pseudonym), as described briefly below.

Ashraf held strong views that this study was much-needed research and narrated two profound experiences to illustrate this. As a wheelchair user, Ashraf narrated his experience of attending his local Masjid. Despite the supposed wheelchair-accessibility, Ashraf described the many difficulties in accessing the space beyond the entrance ramp:

However, once you enter the mosque, it is difficult to manoeuvre around or get to the front of the mosque as there are shoes strewn all around the place². Every mosque has a designated space where the people attending the mosque are expected to place their shoes. (But instead) the shoes that are all over the place prevent the person in the wheelchair from getting to the front of the mosque, thus taking away his choice of free movement.

This example highlighted the need to explore how the actions of Muslims in Masjid may limit persons with disabilities from moving to the front of the Masjid or even from being part of the main congregation, as the shoes are often placed in the way. Ashraf had to pray wherever the mass of shoes ended, taking away his choice of where in the Masjid he prayed. This highlighted a possible lack of sensitivity and basic human understanding by congregation members who leave their shoes randomly lying about at the edge of the prayer mat. Relating his second experience, Ashraf recalled his observations of another person with a disability in the same Masjid. Dawood (pseudonym) rests his crutches near to him when he prays. However, on one occasion he happened to place them in the area where others placed their shoes. People arriving after him then placed their shoes on his crutches, making it difficult for him to get to them.

² One has to remove shoes when praying, so shoes are removed and placed on a shelf before one gets onto the prayer mat.

These descriptions related to one Masjid, raised my concerns about how disability inclusion was experienced and practised within the Muslim community more broadly. Added to these experiences, my engagements with students drew my attention to the further challenges faced by Muslim students with disabilities who expressed their frustrations at not being able to access the prayer facilities at the University of Cape Town. As a Muslim woman, this was close to home for me. The prayer facility was not only a space where individual and communal prayers were held but it was also the main meeting and natural socialising space for Muslim students. Students further reported that most meetings and socials were held in venues that were inaccessible to students with disabilities.

When South Africa became a democracy, the promotion and protection of human rights became enshrined in the South African constitution. Realising these rights for persons with disabilities in all parts of the South African population including Muslim South Africans became imperative. My experience with my group of friends with disabilities once again highlighted that this was an issue that required focussed attention through research.



Figure 1. 1: *This picture depicts Dawood's crutches placed neatly on the side*

1.4 DISABILITY IN THE UMMAH

The word *Ummah* is an Arabic word describing a people or a community of believers (Hadi & Mu'ammad, 2020; Hassan, 2006; Numrich, 2012). It originates from the Quran and for this reason is very significant to Muslims (Hassan, 2006). According to Islamic scholars, the Muslim world is seen as a universal community of Muslim believers and this constitutes one 'Ummah' (Hassan, 2006; Souleimanov, 2018). Equality of all humans is promoted as the will of God Almighty in the Muslim Ummah and emphasis is placed on intent and corresponding conduct (Widinarsih, 2017). Mutual respect of fellow human beings is valued as essential (Widinarsih, 2017) with discrimination based on race, ethnicity, gender or disability explicitly discouraged.

Islamic values which should be reflected in the Muslim Ummah include benevolence, care for others, co-operation between individuals, empathy, justice, social support and positive human relations (Kelly, Aridi, & Bakhtiar, 1996). Responsibility rests with each Muslim to uphold these values since every Muslim has a responsibility to protect and safeguard the community (Haynes, Eweiss, Mageed, & Chung, 1997). To build the ideal, strong unified, disability inclusive Ummah family and community, members should ensure justice for all persons with disabilities. In Islam there are vivid examples of equality and justice for persons with disabilities, however, it is the disjuncture between the Islam perspective of disability and cultural practices that result in the exclusion of persons with disabilities within the Ummah (Al-Aoufi, Al-Zyoud, & Shahminan, 2012).

Hassan (2006) explains that the Ummah became a framework intended for maintaining religious unity and accommodating the cultural (and other) diversities of all its believers (Hassan, 2006). One of the key values for a Muslim is building human relations through developing a strong collective solidarity or Ummah. What this encompasses is the consciousness of belonging to a community whose membership is open to all, without any need or restrictions, embodying the universalism of Islam (Hassan, 2006). In viewing the concept of Ummah, individuals develop a sense of collective identity by identifying with and internalising the values, goals and purposes of the community they belong to. Rituals and ritualised behaviour further reinforce this collective identity and provide the members of this group with a sense of similarity, especially against the 'others' whose collective identity is different (Hassan, 2006). The Muslim community in South Africa includes people from diverse cultural, ethnic, geographical and race groupings and with different identities and abilities. The practice of the religion of Islam binds this group into the Ummah of Islam. Muslims with disabilities, in identifying with the values, goals and rituals of the Ummah, are 'supposed' to be part of this collective identity yet may not always be as a result of their impairment.

In keeping with the core values of an Ummah, persons with disabilities should feel a part of the Ummah and should be able to actively participate in all its activities if they wish to do so. If persons with disabilities have equitable access and opportunities just as non-disabled

members of the community, they then have the choice to participate in the social activities as well as the religious practices within the Ummah.

However, while some people try to maintain this 'ideal Ummah', many fall short, for example, in the inclusion of persons with disabilities within the Ummah. Whether this is intentional or simply that non-disabled persons have not consciously thought through the full inclusion of persons with disabilities within the Ummah, is a question that this study seeks to address. Is it time to challenge the Ummah rhetoric and question whether we have moved away from the original concept of the Ummah?

1.5 RESEARCH QUESTION, AIM, OBJECTIVES

A knowledge gap exists in detailing the experiences of persons with disabilities within the Muslim Ummah, with no such studies having been conducted in South Africa. Furthermore, no literature was located which explores the impact of Islamic principles on Muslim practice in respect of persons with disabilities (M. Miles, 2000). The academic research on disability in Islam is scant and this field can be seen as still in its embryonic phase (Ghaly, 2016).

This lack of knowledge around disability and in particular, the absence of voices of persons with disabilities and their experiences within the Ummah, results in the marginalisation, stigmatisation and the exclusion of persons with disabilities within the Muslim Ummah. Persons with disabilities continue to remain on the margins within the Muslim Ummah and are simply expected to 'fit in' within the broader Ummah.

Given the understanding that religion plays the same role in the lives of persons with disabilities and their families as in non-disabled persons (Imhoff, 2017; O'Hanlon, 2013), researchers need to explore the activities and behaviours within religious communities related to disability for overall participation and inclusion (O'Hanlon, 2013). This study therefore aims to respond to the research question: "How is disability inclusion interpreted, experienced and enacted by people within the Muslim Ummah in South Africa?" The aim of the study is to gain insight into how disability inclusion is enacted within the Muslim Ummah in South Africa.

The objectives of the study are to explore:

- the interpretation and experiences of disability inclusion by persons with a physical or sensory disability within the Muslim Ummah;
- the interpretation and experiences of disability inclusion by the Ulema within the Muslim Ummah;
- the interpretation and experiences of disability inclusion by families of persons with disabilities within the Muslim Ummah;
- the interpretation and experiences of disability inclusion by non-disabled persons within the Muslim Ummah.

Importantly, this study does not focus on the theological aspect of disability as mentioned in the Quran and Hadith, although mention is made of certain examples in the Quran and Hadith that are pertinent to the study. It is anticipated that this study will provide insight into disability inclusion within the Muslim Ummah in order to identify possible opportunities for promoting the full inclusion and belonging of persons with disabilities within the Muslim Ummah. It provides a platform for the voices of persons with disabilities to be heard, and it creates a space for the views of non-disabled persons (including the Ulema) within the Muslim Ummah to have honest, open conversations around disability, challenging the myths and stereotypes that have dominated the discourse around disability. Further, it helps find ways to move forward towards the full inclusion and belonging of persons with disabilities within the Ummah in South Africa. It is also anticipated that the study will identify the need for a re-shaping of disability thinking through knowledge creation.

1.6 REFLECTION ON AN UNEXPECTED EVENT-COVID-19

An unexpected development occurred while in the process of writing up the research study. In March 2020, the World Health Organisation (WHO) declared the coronavirus disease, a communicable respiratory disease caused by a new strain of coronavirus, a global pandemic (Anjorin, 2020; Sohrabi et al., 2020). Commonly referred to as COVID-19, the disease causes illness in humans which may be exacerbated by non-communicable diseases (NCDs) such as chronic obstructive pulmonary disease (COPD), heart disease, hypertension and diabetes (Guan et al., 2020). These NCDs are also known to have a strong association with disability

(Prynn & Kuper, 2019). The impact of COVID-19 on people in all works of life, including researchers, has brought about life-changing experiences that include despair and helplessness (Fessell & Cherniss, 2020; Galea, Merchant, & Lurie, 2020; Holmes et al., 2020).

The lockdown resulting from the pandemic saw many freedoms curtailed in a multifaceted manner. Although not directly related to this study and not part of the study objectives, the researcher feels that it is important to reflect on this issue as it reflects the experience of exclusion highlighted within the study. For Muslims the world over, the closure of the Masjids was unprecedented and created great distress within the Muslim Ummah. Of significance to this study is the response by Muslims, in particular in South Africa, to this lack of freedom to attend the Masjid and the impact this had on their spirituality.

The freedom of access to the Masjid was completely denied during the initial lockdown phase and subsequently was curtailed. This was an extraordinary time in the lives of people globally and the Muslim Ummah was deeply impacted. Many of the Musallies who attended the Masjid regularly were powerless in this situation. The power balance shifted from the leadership within the Masjid to the government, with the government deciding on behalf of all Muslims regarding attendance at the Masjids. This exclusion and lack of freedom to attend the Masjid may be likened to the way persons with disabilities often feel. Those leaders who once held the power to make decisions on behalf of others, and in this instance for persons with disabilities, had that power removed, so much so that they took the matter of opening the Masjids to the courts for permission to be allowed to pray within the Masjid (Southern African Legal Information Institute, 2020). The people entrusted with the running of the Masjids felt that they were failing in their obligation to Allah when they were not allowed to pray in the Masjid, especially in the holy month of Ramadaan. Their freedom of choice was compromised. And yet, this exclusion from meaningful spaces for persons with disabilities has been deeply rooted within the Ummah without much thought being given to the impact this exclusion might have on them.

1.7 OUTLINE OF THE THESIS

This chapter focuses on the background and evolution of the study. It introduces the concepts of inclusion and Ummah and presents the problem statement, research purpose and aims and objectives of the study. Chapter two reviews literature around religion and disability and, in particular, Islam and disability, underpinning disability inclusion within the religious communities. Chapter three discusses the theoretical frameworks which guide the study, namely The Capability Approach, Perspectives of De-coloniality and Ableism.

Chapter four presents the methods used in gathering data for this study. Chapter five presents the findings of the study and Chapter six discusses the findings of the research. Finally, Chapter seven focuses on the conclusion, summary and recommendations for future research.

CHAPTER TWO: LITERATURE REVIEW

This chapter begins with a discussion of the way disability inclusion has been framed in literature, highlighting the limitations of various models of disability in framing this concept. This is followed by an explanation of how disability inclusion is considered across religious communities and, specifically, within the Muslim Ummah. It offers insights into the history of Islam in South Africa and the understanding of how social exclusion of persons with disabilities has evolved, highlighting the role of agency in dealing with this challenge.

2.1 FRAMING DISABILITY INCLUSION

This section discusses interpretations of disability as an entry point to explaining the concept of disability inclusion. The usefulness of current models of disability for informing understanding of disability and disability inclusion are elaborated upon.

Interpretations and definitions of disability shape the way disability inclusion is conceptualised. Over the years, there has been much debate about the definitions of disability with varying propositions being put forward. However, there is still no consensus (Ghaly, 2016). Traditionally, most of the definitions have viewed a person with a disability in a negative light (Hinojosa, 2018; Retief & Letšosa, 2018) by equating the limitations leading to the disability with the person (Saleeby, 2007). Such definitions risk disregarding the perspectives of persons with disabilities by emphasising their body and/or mind impairments and the functional limitations that result from their health conditions (Hinojosa, 2018; Reddy, 2011). Their focus is not on the person but on their impairment.

The medical model of disability identifies disability as a consequence of a health condition, reflecting little distinction between how disability is conceptualised by the health care services that a person may require (Bennett & Volpe, 2018). This perspective locates disability within the individual body, characterised as pathology with a focus on what is seen as lacking in the person and their body and its diseases. It pays little attention to the way the person participates in society (Reddy, 2011). In viewing impairment as a 'problem' of the person with a disability that needs to be 'cured,' thus objectifying the person with disability as someone who requires special help and care (Retief & Letšosa, 2018). The person and their body are

seen as abnormal and thus, necessitating the person to be subjected to medical intervention (Andrews, Ayers, Brown, Dunn, & Pilarski, 2020; Burton, Sayrafi, & Srour, 2013; Chappell, Goodley, & Lawthom, 2001; Dokumacı, 2019; Evan, 2020; Goering, 2015) to cure this 'abnormality'. Hinojosa (2018) describes this as the need to mitigate the deficiency. This is a very narrow, limiting lens through which disability and a person with a disability are viewed (D'Souza, 2020; Mitra, 2018). It emphasises curing, finding a solution or attempting to 'fix' the disability in order to 'return' the 'patients' to their communities (Ghaly, 2016; Hinojosa, 2018). This view often deprives persons with disabilities of their dignity and agency since it limits any concept of their control (Hinojosa, 2018). This is informed by a view of disability where persons with disabilities are seen as deviating from what is considered as 'normal' (Retief & Letšosa, 2018). The focus is then on bringing in the concept of normality by fixing the characteristic that is considered 'abnormal' (Gebhardt, Schurig, Suggate, Scheer, & Capovilla, 2022). The emphasis being on the individual and what they need to do to assimilate into the normative way of being.

The notion of normality has been at the core of othering processes where disability is interpreted as a physical, moral, emotional, mental and spiritual deficit (Loja, Costa, Hughes, & Menezes, 2013). This normative perspective of disability places the standard of 'normal', denoting an ideal of ability and sameness, as an ideal to strive for and, in contrast, 'abnormal' as being 'different or other' (Garland-Thomson, 2014). Andrews *et al.* (2020) identify this as 'ableist assimilation' or ableism, where persons with disabilities are measured by their capacity to function as a 'normal' person does. Ableism is underpinned by two fundamental elements: firstly, the notion of the normative individual and, secondly, the creation of a divide between an objectified perfect human and a deviant, underdeveloped person, who is seen as poorly fitting this ideal of a human (Bennett & Volpe, 2018; Campbell, 2019). Persons with disabilities are not seen as part of society unless they fit or conform to the 'ideal' portrayed by mainstream society (Bennett & Volpe, 2018). This is experienced as malicious and harmful as it promotes non-disabled persons as representing the norm and an ideal state of being (Andrews *et al.*, 2020). In essence, ableism embodies a mode of control that a non-disabled majority wields over a minority of persons with disabilities whereby the experience, expectations and contributions of persons with disabilities are marginalised or dismissed

(Andrews *et al.*, 2020). The person with a disability is considered a non-entity and their agency diminished. This concept of ableism assists in understanding the oppression, discrimination and marginalisation experienced by persons with disabilities within a non-disabled majority world (Loja *et al.*, 2013). Ableism functions as a foundational form of social oppression, deep and pervasive, resulting in stereotyping, exclusion and segregation (Bogart & Dunn, 2019; Fine, 2019). A consequence of this ableist rhetoric is that persons with disabilities experience feelings of being undervalued, excluded and pressured into fitting a norm (Goering, 2015; Scullion, 2010).

Ableism, supported by perspectives from the medical model, deflects from the larger social and structural problems that limit disability inclusion (Imhoff, 2017) by ignoring disability as a category of social identity contributing to intersectionality (Evan, 2020). The message that ableism reinforces is that the lives of non-disabled persons are more worthy than others. This is evident in policies and practices. For example, it is illustrated in decisions about access to medical intervention in extreme circumstances such as in the COVID-19 pandemic (Andrews *et al.*, 2020). Another example showing the influence of ableism is the dominance of focus within services offered by health care professionals, like doctors, nurses and social workers, on the functional limitations of the individual (Burgstahler & Doe, 2004; Zakaria, 2020) without attending to the systemic need for disability inclusion within society. This ableist perspective of disability is seen as playing a critical role in invalidating bodies that do not conform to the norm (Loja *et al.*, 2013). Persons with disabilities face exclusion as a result of society's perception of disability (Barnes & Mercer, 2010, as cited in Burton *et al.*, 2013). This creates a divide between persons with disabilities, who have little to no voice in a mainstream society dominated by non-disabled persons, and a discourse of able-bodiedness. It also continues, through medical interventions, to perpetuate the expectation of ableist assimilation (Chappell *et al.*, 2001).

The International Classification of Functioning, Disability and Health (ICF) (Saleeby, 2011) was developed in order to collect information about the health of populations globally (Mitra, 2018), by providing a unified framework using the standardised language set out by the World Health Organisation, describing functioning and disability associated with health-related

conditions (Heerkens et al., 2018; Johnson-Migalski & Drout, 2018; Mitra, 2018; Saleeby, 2011). The ICF improved on the previous International Classification of Impairment and Handicap (ICIDH) by paying greater attention to the enablement of persons with disabilities (Heerkens *et al.*, 2018; Johnson-Migalski & Drout, 2018). The ICF is considered a bio-psycho-social model (Heerkens *et al.*, 2018; Mitra & Shakespeare, 2019), transcending the contrast of the two competing models viz. the medical and social models (Mitra & Shakespeare, 2019). It offers function, activity and participation to replace the concepts of impairment, disability and handicap (Johnson-Migalski & Drout, 2018). Within the ICF framework, health conditions are considered amongst multiple factors, emphasising that the construct of disability is the outcome of complex relationships amongst key domains (Johnson-Migalski & Drout, 2018).

For the ICF, the lack of inclusion includes activity limitations and participation restrictions and it is the result of the interaction between the health of a person and their health condition, as it occurs in particular environments (Johnson-Migalski & Drout, 2018; Mitra, 2018). An activity is seen as the accomplishment of a task by an individual and participation is understood in terms of involvement in a life situation (Mitra & Shakespeare, 2019; World Health Organization, 2011).

While the ICF attempts to incorporate both the medical and social models' perspectives of disability (Mitra, 2018; Mitra & Shakespeare, 2019; Mji, Rhoda, Statham, & Joseph, 2017), the focus on health, diagnosis and classification still tends to overshadow the impact of environmental and societal barriers to persons with disabilities. Barnes (2011) posits that the ICF does not take sufficient cognisance of the interaction between activities and participation and environmental and personal factors, thus limiting the extent to which disability inclusion may be advanced. There is a concern that the ICF is too person-centred and that the emphasis on activities and participation appears limiting (Mitra & Shakespeare, 2019). Mitra and Shakespeare (2019) further maintain that activities and participation should be expanded to include a more holistic concept of quality of life or well-being, things that a person values. The Capability Approach is a framework that has been suggested in relation to the ICF. It is an approach that defines quality of life in terms of capabilities, which are the real opportunities to do and be what one has reason to value (Heerkens *et al.*, 2018; Mitra & Shakespeare, 2019).

In order to address the concern related to broadening the understanding of participation, the definition of inclusion used in this study where disability inclusion refers to the full inclusion of persons with disabilities within all spheres of society is useful. The definition of disability inclusion thus states that persons with disabilities have access to opportunities that enable them to play roles of their choice within the social networks to which they belong and where they may give and receive support (Cobigo *et al.*, 2012; Rimmerman, 2013).

Mosleh (2019) argues that by focusing on the idea of a biological (able) body, what the ICF does is falsely construct impairment as being inherently and naturally inferior. In so doing, it indirectly places the blame on the impairments themselves as being the primary source of harm experienced by people who have the impairment; the impairment is seen as negative and requiring intervention. The language of limitations and the focus on health-related conditions still appears to be embedded in the definition of disability within the International Classification of Functioning as a construct of concern with regard to individual health.

Heerkens *et al.* (2018) state that while the ICF is still imperfect as personal factors are not currently classified and the dominant position is still the medical perspective, nevertheless, it provides a common denominator for describing current, societal developments. They recommend that in order for the ICF to move beyond its emphasis on impairment and health care and to enhance its implementation throughout disciplines and professions, a revision of the ICF is needed (Heerkens *et al.*, 2018). This revision of the ICF is supported by (Mitra & Shakespeare, 2019).

The social model of disability rejects the medical categorisation of ability as the basis for conceptualising disabilities, but rather focuses on the removal of discriminatory barriers, emphasising social integration and self-determination (Loja *et al.*, 2013). Some critics argue that the social model disregards the painful realities associated with some impairments (Retief & Letšosa, 2018). However, proponents of the social model of disability recognise that, while certain illnesses may have a disabling consequence and that medical professionals play a necessary role in treating these illnesses, distinguishing between people's illnesses or impairments and their disabilities remains important (Retief & Letšosa, 2018).

The social model of disability makes a clear distinction between disability and impairment (Chappell et al., 2001; Loja et al., 2013; Mizrachi, 2014). The social model of disability proposes that persons with disabilities are not disabled by their impairment and that disability is not an individual attribute, but that disabilities result from disabling barriers created within society (Gebhardt et al., 2022; Mitra, 2018; Mike Oliver, 2013). The view is that, while an impairment may create certain personal restrictions, it is the hostile cultural, social and environmental barriers that create the disability (Mike Oliver & Barnes, 2010). These disabling barriers include social disadvantage, discrimination and exclusion based on a person's abilities (Mitra, 2018). An important contribution of this perspective is that it acknowledges, albeit to a limited extent, the reality of the impairment (Swain & French, 2000). It emphasises that impairment does not cause disabled persons economic and social disadvantage (Mike Oliver & Barnes, 2010). The impact of the external, disabling barriers is that persons with disabilities are limited from fully participating in the societies in which they live (Loja et al., 2013; Mike Oliver & Barnes, 2010).

Disabling barriers within society prevent certain bodies from fully accessing society and privilege certain bodies, that is non-disabled bodies over different bodies, in other words, those of persons with disabilities (Hinojosa, 2018). The social model of disability proposes that societies have a responsibility to ensure that structural barriers are removed to create an accessible environment for persons with disabilities. The main crux of the social model of disability is thus the modification of the disabling society (Mizrachi, 2014) and removing socio-environmental barriers that limit access, rather than focusing on the individual as being non-conforming (Zakaria, 2020). Attention is also given to the attitudinal barriers faced by persons with disabilities (Goering, 2015). Scullion (2010) contends that this implicates collective responsibility for thinking and acting in societies to move away from excluding persons with disabilities. It distances disability from being the concern mainly of the personal, private and medical arena and places it in public and political spheres, thus giving prominence to the notions of rights and responsibilities (Scullion, 2010). It underscores the significance of collective action of all members of society in dismantling disablement to creating an all-inclusive society (Chappell et al., 2001). Karangwa, Miles, and Lewis (2010) report on the

outcome of a study exploring the meaning of community and community solidarity and perceptions of disability in three areas in Rwanda (two rural and one urban).

This study found that the manner in which children with disabilities were treated by their families had a strong impact on the way they were accepted in schools and society (Karangwa et al., 2010). This draws attention to the impact that family perceptions have on the way the wider community perceives disability and how this can lead to inclusion of children with disabilities within the community and schools. It also highlights the importance of working with community leaders and extended family members to change perceptions of disability and, at the same time, giving adequate attention to cultural beliefs and traditions. It is noted that it is important to work with the community with regard to those beliefs that strengthen inclusion and challenge those that inhibit inclusion (Karangwa et al., 2010). This highlights the potential significance of the collective action of both persons with disabilities and non-disabled persons working together, as a unified collective, to create an inclusive society. It highlights the possibility for changes in attitudes towards disability and inclusion to occur when people work together. Although much work still needs to be done to create inclusive societies, the shift from the medical to the social model of disability has brought about significant and positive social and political change within the disability sector (Hinojosa, 2018).

Within academia, the social model has allowed for the emergence of the interdisciplinary field of disability studies, allowing for debates (Bennett & Volpe, 2018; Gabel & Peters, 2004; Imhoff, 2017; Mike Oliver, 2013) and scholarship focused on disability inclusion to emerge. Scholars within the disability studies' field have lamented the limitations of the social model (Sang, Calvard, & Remnant, 2022) and called for possible alternatives to the social model (Gabel & Peters, 2004). A criticism of the social model is that differences and impairments are not taken into consideration. Instead, persons with disabilities are viewed as a homogenous group (Mike Oliver, 2013). By not acknowledging the diversity of experiences of disability, there is the presumption of a 'normal' way of being a person with a disability, with an emphasis on sameness (Bennett & Volpe, 2018; Imhoff, 2017). Imhoff (2017) further argues that proponents of the social model should consider religious texts, practices, communities in their discourse around the barriers that construct disability within society and the

importance that these hold for many persons with disabilities. Religion plays a crucial role in the way mental and bodily status is viewed and how this is seen in relation to disability (Imhoff, 2017).

In response to the many critics of the social model, (Mike Oliver, 2013), a key proponent of the social model, agrees that the social model might be lacking in many areas that its opponents criticise it for. It is seen as one of the most discussed, criticised and revised statements in the area of disability studies (Mladenov, 2022). However, Mike Oliver (2013) contends that it was meant to be a tool to improve people's lives (Mike Oliver, 2013), providing a space for activism, agency and for the voice of persons with disabilities to be heard. The social model has impacted greatly on current policies in the field of disability. Furthermore, while there are critiques of both the medical and social models of disability, focusing on the gaps of both models, there is no consensus of what a broader framework of disability should encompass (Mike Oliver, 2013).

2.2 COLONIALISM AND DISABILITY

Colonialism refers to political, economic, cultural domination where one nation has power over another, in particular, the global North over the global South (Maldonado-Torres, 2007; Meekosha, 2011). Persons with disabilities, like non-disabled persons, are part of the history of the colonised (Grech, 2015). In the case of disability and colonialism, persons with disabilities, in a similar way to racialised individuals, have been institutionalised or separated from mainstream society in order to advantage, and perhaps protect, non-disabled persons (Meekosha, 2011). While the idea of institutionalisation of persons with disabilities may not be as prevalent as it was in colonial times, this kind of 'othering' of persons with disabilities still continues within communities, with the marginalisation and exclusion of persons with disabilities within society. Grech (2015) states that when colonisers started to encounter the other, they needed to construct the other racially, culturally, bodily and spiritually.

Colonialism is not just an event that can be relegated to the annals of history but it still matters as it continues to provide foundations for ideological, cultural and material domination (Grech, 2015). The dominance of the ableist, colonial way of interpreting

disability and disability inclusion, has a bearing on the way disability inclusion may be enacted. Ableism emphasises the belief that disability and impairment are inherently negative and should be ameliorated or cured (Campbell, 2008). Colonial thinking is evident within the ableist discourse, in that, whatever goes against the expectation of a 'normal', 'perfect' body is still considered as inferior. It has been proposed that the disabled body is necessary to construct and sustain the normative, normal, idealised, non-disabled body (Grech, 2015). The concept of normativity is taken as a yardstick against which to measure people, in much the same way that the global North (civilised, coloniser) needed the 'other', global South (uncivilised, colonised) to perpetuate the existence of binaries.

2.2.1 Religion and Colonialism in South Africa

The 2001 South African Census data reports that Muslims make up approximately 1.46 % of South Africa's 44.8 million people (Vahed, 2021). The arrival of Islam occurred within the context of colonial settlement and slavery and has an intricate history of race in South Africa (Baderoon, 2014). Slavery and Islam are closely linked in South Africa. The arrival of the first Muslims in the Cape Colony as slaves and 'free slaves' dates back to 1658 and most Muslim people of Indian heritage arrived as indentured labourers to the then colony of Natal (Kwa-Zulu Natal) between 1860 & 1910 (Baderoon, 2014; Vahed, 2021). Muslims were also brought to South Africa as a result of a shortage in labour in Natal, which was then under British rule (Palombo, 2014).

During this period, Islam became a refuge for the enslaved indigenous Khoi and San people, forming an indigenous Muslim community in the Cape. With the different groups being part of the Muslim community, there was a racial indeterminability in the meaning of Muslim in SA. The Muslim community is made up of Malays, in the Western Cape and Indians, mostly in Kwa-Zulu Natal and Gauteng as well as the indigenous Muslim community (Baderoon, 2014). Muslim migrants to Natal (KwaZulu Natal) were incorrectly called 'Arabs' because of their religion and dress (Vahed, 2010). While the term 'Cape Malay,' a term used to refer Muslims from the Cape suggesting a certain geographical origin of this group within the Muslim community, coming from Malaysia, the connotation is much more complex. It was a

term used to describe the enslaved Muslims brought by the Dutch to the Cape. Presently, the descendants of the slaves in the Cape are often called 'Cape Malays' (Baderoon, 2014).

Muslims experienced the harshness of slavery and colonialism even being forbidden to practice Islam. These Muslims were discriminated against for practicing their religion, emphasising the colonial preference for Christianity as the religion of choice (Wallace, 2015).

The construction of separate racialised identities in the 19th Century continued in the 20th Century with the 'reinvention' of 'Malays' along racial lines particularly in the Cape (Baderoon, 2014). Mashau (2018) expands the understanding of de-coloniality, not only as a political, economic, educational and social project but as also a faith project and claims that the involvement of faith-based communities is critical in the de-colonial project.

The strategy of colonialism was to eradicate cultural beliefs, knowledge, customs, languages, indigenous communities and traditions through the introduction of alien cultures from the global North. One of the ways in which this was done was through the Christian missions of spiritual indoctrination and domination (Grech, 2015). Under British colonial rule, the spread of Christianity through the conversion of Africans to Christianity was introduced in mission school education. The idea was to replace widespread African traditional beliefs and practices through converting people to Christianity. Islam and Hinduism, religions that have a significant presence in South Africa, were both subject to discrimination and experienced the destructive presence of Dutch and British colonialism and white Christian apartheid, similar to other subaltern communities, with the colonial belief that one particular religion was the only right religion (Palombo, 2014; Wallace, 2015). Different groups of colonists established their own specific settler churches where inclusion depended on the adherence to Christian orthodoxy (Wallace, 2015).

As an extension to colonialism, with apartheid, the colonial powers considered 3 elements to be threats- 'die swart gevaar' (the black threat), 'die rooi gevaar' (communism), and 'die slamse gevaar' (Muslims) (Haron, 2006). The white missionaries of the time tried to convert

the Muslims to Christianity with the growing Muslim population considered a threat to the then dominant white, Christian rulers (Haron, 2006).

The apartheid government's political philosophy was entrenched in the religious tenets of the Christian Dutch Reformed Church (NGK), which biblically justified the government's practice of racial segregation (Palombo, 2014). Their belief was rooted in their religious dogma and they considered themselves superior to all others in all respects. The apartheid ideology was rooted in the belief in the dominance of those they considered as being 'below' them. To the white people, all non-white persons (Africans, Coloureds and Indians) were viewed as racially and intellectually inferior. As such they implemented policies that clearly discriminated against these groups. Because, according to the dominant white group, this was firmly embedded in their religious belief system and God's plans, no one was allowed to question this interpretation.

However, there were a number of young Muslim activists who challenged the missionaries of that time and challenged the rhetoric that Islam was considered a 'false religion.' (Haron, 2006).

2.3 RELIGION IN DISABILITY STUDIES

A remnant of colonialism, as Meekosha (2011) claims, is the dominance by the global North in writing about disability without giving much credence to the experiences of disability from the global South. This results in an absence of the voices of theorists from the global South, thus contributing to perpetuating marginalising experiences of disability in the South (Meekosha, 2011; Ned, 2022). A further limitation of the disability studies' scholarship is the absence of religion and the experience of disability within faith-based organisations and indigenous communities. Religion is rarely mentioned in disability studies and there is no sustained discussion of religion, spirituality and disability (Imhoff, 2017). Often religion and spirituality are confused (Ojok & Musenze, 2019). Scholars in the religious and theological fields have expressed their concern that the importance of religion (and spirituality) in the lives of persons with disabilities is not given enough attention in disability studies (Bennett & Volpe, 2018; Imhoff, 2017).

When discussions around understanding disability from the South do take place within disability studies, there is a prevailing narrative that the understanding of disability within an indigenous belief system is rooted in the deficit narrative (Ned, 2022). However, Ojok and Musenze (2019) contend that in ancient Africa persons with disabilities were not seen in a negative light and were accepted within the community. In Islam, as well, there are many examples of justice and equality for persons with disabilities as mentioned earlier (Al-Aoufi et al., 2012).

Persons with disabilities do experience different forms victimisation in African communities, however, Ned (2022) posits that these contemporary mistreatments and negative myths and stereotypes of disability are not necessarily a reflection of African cultures, rather a symptom of the colonial encounter (Ned, 2022). The exclusion experienced by Muslims with disabilities could also lend itself to the influence of coloniality on the way the Muslim Ummah view persons with disabilities.

2.3.1 Religious Perspectives on Disability Inclusion

Imhoff (2017) maintains that religion and spirituality provide meaning and are central in the lives of many people, including persons with disabilities (Imhoff, 2017; Möller, 2012; Mugeere, Omona, State, & Shakespeare, 2020). Studies indicate that in many societies religion and spirituality often play an important role for persons with disabilities (Möller, 2012). However, scholarly work on religion and disability is very rare (Imhoff, 2017) with a dearth of contributions from Catholic theologians (Iozzio & Romero, 2017) and Islamic scholars and theologians (Ghaly, 2016). Where literature is available on disability and religion, it is primarily from a Christian perspective (Creamer, 2012) often with the emphasis on 'curing' or healing of the person with a disability (Retief & Letšosa, 2018). Imhoff (2017) contends that understanding the relationship between religion and disability can bring new understanding into the disability studies discourse (Bennett & Volpe, 2018). However, it is acknowledged that currently religion often casts a negative perspective of disability in the disability discourse (Imhoff, 2017). This may be because religion is often seen as creating or upholding the normative thinking associated with ableism, with disturbing ways of viewing disability reflected in religious traditions (Bennett & Volpe, 2018; Imhoff, 2017). Even within

scholarship that might be sympathetic to religion, Judaism, at times, bears the brunt of critique and Imhoff accedes that this, in part, might be warranted as the Talmud and other rabbinic writings sometimes assign lesser religious statures to persons who are, for example, intellectually disabled or Deaf and equates physical disability with 'impurity' (Eiesland, 2005; Imhoff, 2017). However, a common thread between Christianity, Islam and Judaism is the agreement that Allah/ God is sovereign over all His creations, including persons with disabilities (Mugeere *et al.*, 2020). The moral implications of long-standing, ableist religious perspectives may also contribute to disabilities being seen as a punishment from God for sin/sins committed by the person with the disability or as a test of faith, seen as either good or bad (Imhoff, 2017; Retief & Letšosa, 2018). This leans towards the medical perspective of looking at disability as something that needs to be eradicated or cured. Persons with disabilities may also be considered to be 'blessed' as they have the opportunity to learn lessons that non-disabled persons do not have the opportunity to learn (Retief & Letšosa, 2018). Notwithstanding, religion may provide coping resources that give meaning to difficult life circumstances and provide a sense of purpose (Koenig, 2012). For those that hold strong beliefs, religion often provides an optimistic worldview that may involve the existence of a higher power (Allah, God, Jehovah etc.) who loves and cares about humans and is responsive to their needs (Koenig, 2012). Thus, the relationships between religion, health and disability and religious bodies are significant and have the potential for the advancement of human conditions as they relate to society (Ihssen, 2020).

When disability inclusion is discussed in the light of Judeo-Christian theology, there is a mixture of many different conceptualisations of disability at play. Even though it might appear that much of the Bible contains negative imagery of persons with disabilities (Selway & Ashman, 1998), positive conceptualisations of disability - in the modern sense - have emerged from Christian theology (Schuelka, 2013). Many persons with disabilities have been treated far more kindly by social service institutions run by the church than they would have been in state-operated prisons and asylums (Blanks & Smith, 2009). Disability is portrayed very differently in the New Testament than in the Hebrew Bible (Schuelka, 2013). However, it should be noted that interpretation of the Bible is an evolving process, often used to serve the persona of the interpreter (Danforth, 2005). This means that the interpretation of

disability may be explained differently by different interpreters and enacted differently in its impact on disability inclusion. With regard to religious institutions, such as the church, it is contended that disabling theology that denies justice and inclusion for many of 'God's children' severely limits persons with disabilities from participating within these spaces (Eiesland, 2005). The manner in which many Christians today continue to understand scripture and explain theologies reinforces negative stereotypes of disability where persons with disabilities are seen as 'deficient' or 'helpless', where the person with a disability is viewed from the charitable model of disability. This reinforces social and environmental segregation and conceals the lived realities of persons with disabilities (Eiesland, 2005; Reynolds, 2012). Eiesland (2005), a forerunner in engaging with religion and disability, states that the church has been a physically inaccessible and inhospitable space for many persons with disabilities (Eiesland, 2005). When religious communities create access for persons with disabilities, it is said to occur in a paternalistic manner, dominated by the non-disabled bodies who 'welcome' persons with disabilities in a space that should equally belong to all congregants (Eiesland, 2005; Reynolds, 2012). Once again underscoring the charitable view of disability.

Some Christian leaders criticise the church for its failure to provide clear and adequate teaching that focuses on disability issues, even though some churches have tried to promote equal opportunities for persons with disabilities (Treloar, 2002). While acknowledging that disability theology has definitely made progress, there is still much work to be done (Creamer, 2012). What is needed is to develop a liberating theology of disability which identifies and confronts the crucial elements of the church's disabling theology (Eiesland, 2005). There is well placed concern by disability rights' advocates around the paternalistic relationship and the power imbalance between persons with disabilities and Christian charity and evangelism (Schuelka, 2013). Even when theology advocates for access, it is normally the voices of non-disabled persons that speak on behalf of persons with disabilities, not permitting the voices of persons with disabilities to be elevated and heard.

Although sharing similarities with Judeo-Christian monotheism, Islam differs in the way it conceives of a person's relationship with God in the sacred text of the Qur'an where disability

seems to be positively regarded. A crucial narrative within the Quranic understanding is that importance is not placed on the physical abilities of a person in their connection with God, rather, the relationship is about the degree of submission to God's will and about fulfilling God's commandments to the best of one's ability (Ghaly, 2016). However, the interpretation and enactment of these sacred texts by Muslim people may still result in negative experiences for persons with disabilities within religious spaces (Schuelka, 2013), as an ableist perspective remains persistent.

Thus, it appears that although the holy scriptures related to disability guide focus towards spirituality rather than impairment, there seems to be a disjuncture between scripture and practice with the focus still, in most cases, on appearance and the ability of the person to fit into the mainstream of the community. In a study carried out in Victoria, Australia, on the experiences of persons with disabilities and faith leaders from Buddhist, Christian, Jewish and Muslim perspectives, one participant, who was Deaf, spoke about the need for an interpreter to assist with further understanding of Islam. Isolation of persons with hearing impairments within religious spaces was found to be an issue, especially where Australian Sign Language was the person's first language (Calder, 2012). Unfortunately, instead of empowering persons with disabilities, the church has most often facilitated the treatment of persons with disabilities as objects of pity, in a paternalistic manner (Eiesland, 2005). In a study carried out by Don, Salami, and Ghajarieh (2015) with youth with disabilities, it was found that the focus on their physical differences was a constant reminder of their 'otherness.' Their stories told of being the objects of pity (Don et al., 2015).

2.4 UNDERSTANDING OF DISABILITY AND DISABILITY INCLUSION WITHIN RELIGIOUS COMMUNITIES

2.4.1. Understanding Disability and Disability Inclusion within the Arab Countries

In Arab societies, such as the United Arab Emirates, Egypt, Oman and Saudi Arabia, where Islam originated and is the main religion, historical understandings of disability was fraught with confusion, misunderstanding and doubt, leading to stigmatization and oppression(Alkhouli, 2015; Saad & Borowska-Beszta, 2019). This stigmatisation was marked

by inferiority, neglect, contempt, abuse and negligence. Persons with disabilities were subject to many negative experiences within society with prejudiced beliefs about disability including that persons with disabilities were symbols of sins committed by their parents, “bad omens” (Saad & Borowska-Beszta, 2019). This often led to experiences of rejection and displacement. This is a poor reflection of Islamic principles, which most Arab laws are based upon. Islamic legislation derives its laws from the Holy Qur’an and Prophetic tradition. The Quran states that it is the responsibility and duty of everyone to take care of each other and this is mentioned many times in different contexts. Both Quran and Sunnah have texts and verses that call for the observation of the rights of all members of society, including persons with disabilities (Ali, Bakhiet, Essa, & Alqafari, 2021; Alkhouli, 2015).

In the recent years there has been a shift in the perception of persons with disabilities with a number of policies promulgated in the different Arab countries viz. Saudi Arabia, Oman, United Arab Emirates (Ali et al., 2021; Saad & Borowska-Beszta, 2019) that promote the inclusion of persons with disabilities within Arab Society (Ali et al., 2021; Alkhateeb, Hadidi, & Alkhateeb, 2016; Alkhouli, 2015). The American Disability Rights movement has had an influence on many Arab countries, creating a positive shift in providing support for person with disabilities in these countries. The ratification of the International Convention on Persons with Disabilities has also influenced this shift (Ali et al., 2021). An area where there has been a move in a positive direction to ensure inclusivity is in education. Saudi Arabia has been a forerunner in this respect (Ali et al., 2021). While these policies are encouraging, implementation remains a challenge (Alkhateeb et al., 2016). This remains the case in most countries globally.

2.4.2 Understanding Disability and Disability Inclusion Globally

In Islam, all Muslims, with or without disabilities, are required to participate in religious life and activities. Individuals with disabilities might be excused from religious requirements beyond their ability. However, the individual is clearly not defined socially or religiously by his disability (M. Miles, 2002) but by his actions and deeds as elucidated in the earlier Hadith and, in this way, should enjoy the same rights and responsibilities as all within the Ummah. Within Islam, persons with disabilities are treated as individuals who participate fully within

both the social and spiritual community (M. Miles, 2002) . Once again, this alludes to the understanding of full inclusion of persons with disabilities as indicated by the opportunities for their participation in all activities (Cobigo *et al.*, 2012; Rimmerman, 2013).

Very often persons with disabilities are left out of the mainstream of society because of community members' attitudes and practices. Lack of access to opportunities to participate and negative attitudes towards persons with disabilities often lead to this exclusion. Social stigma is rife and children and adults with disabilities are consequently often considerably devalued (Crabtree, 2007).

Marriage is an important element within society, and it is a practice that is embraced and encouraged in many religions. Persons with disabilities are often not seen as marriageable and people express shock and surprise when they learn that someone with a disability is married. With the understanding of disability from an ableist perspective of 'abnormality' and deficiency, there is the common belief that a woman with a disability will not be able to marry and fulfil her role as wife and mother. Crabtree (2007) indicates that young women, in particular, may find their marriage prospects ruined (Young, 1997) . Female relatives of young women with disabilities are also more likely to be victimised, due to the twin assumptions that the condition is hereditary and that the mothers are fundamentally culpable for a child with a disability. In Jordan, for example, considerable prejudice is shown towards individuals with disabilities and the life prospects of families are reduced by association because of a disability (Crabtree, 2007). Young disabled women have less chance of being married than their male counterparts who are more likely to be engaged or involved in negotiations about marriage (Crabtree, 2007). Parents with a disabled daughter talk about the devastating effect on her marriage prospects, but with sons it is different, there is more hope (Hussain, 2005). This is a further marginalisation and exclusion related to the intersectionality of gender and disability.

There are still high levels of stigma attached to persons with disabilities in the UAE and this stigma extends to mothers who give birth to children with disabilities. The prevailing belief is that it is the mother's fault if she gives birth to a child with a disability and that this genetic

predisposition may be carried forward by her relatives. Similar beliefs are held in other parts of the Muslim world (Atshan, 1997, Boukhari, 1997, as cited in Crabtree, 2007) and there is social embarrassment attached to having a child with a disability in many Muslim families (Al-Aoufi et al., 2012). This places incredible stress and anxiety on the women (Crabtree, 2007; Hamdy, Auter, Humphrey, & Attia, 2011; Williams & Murray, 2015). Mothers of children with disabilities, failing to meet the standardised expectation of motherhood, face typical forms of oppression and marginalisation where a mother of a child with a disability may be excluded by becoming the 'other' within her own category (Williams & Murray, 2015).

Persons with disabilities, including children with disabilities and the families of children with disabilities in many Muslim countries, still face the problem of significant social stigma about disability (Alkhateeb et al., 2016; Crabtree, 2007; Hamdy et al., 2011) and yet Islam emphasises that Muslims with disabilities and non-disabled Muslims should be treated equally (Al-Aoufi et al., 2012). Issues of social inclusion of persons with disabilities still need to be addressed through open discussion.

Persons with disabilities in Ghana described the stigmatisation they experienced within their society in a study looking at societal attitudes towards persons with disabilities. Discrimination, myths, superstitions and negative labels were some of the issues that resulted in the exclusion of persons with disabilities within Ghanaian society, identified in the study of (Baffoe, 2013). The exclusion experienced by persons with disabilities results in their inability and difficulty in meaningfully participating in activities that would ensure their enjoying a good quality of life (Baffoe, 2013), a life that holds value to the person. This exclusion was further highlighted in a study where the experiences of Muslims with disabilities in performing worship revealed many challenges experienced, in accessibility, attitudinal barriers, systematic barriers and invisibilising within the broader Muslim society (Widinarsih, 2017). In trying to use their agency and to voice their concerns about the inaccessibility of the Masjid, persons with disabilities encountered very discouraging responses, namely, that persons with disabilities were not obliged to perform their prayers (salaat) (Widinarsih, 2017). This narrow way of understanding disability within the Islamic religion leads not only to the exclusion of persons with disabilities but it also means that the will to create equal opportunities for

inclusion appears to be minimal. If the understanding is that persons with disabilities are not expected to perform their Islamic obligations, then non-disabled persons will not feel the need to make the necessary accommodations for an inclusive space for persons with disabilities. However, disability inclusion should be seen as being included in the Muslim community without discrimination based on ability (Widinarsih, 2017). This speaks to the understanding of disability inclusion for the purposes of this study.

In a study focusing on the opportunities and challenges faced by persons with disabilities to achieve fulfillment of their religious obligations in Bali, it was found that persons with disabilities continued to face social exclusion in accessing their religious rights with dignity and equality (Gayatri & Juliantari, 2019). This exclusion appears in different forms: discrimination, stereotyping and labelling, and persons with disabilities are still seen as the 'other' in religious spaces (Gayatri & Juliantari, 2019). Similarly, in research conducted by O'Hanlon (2013), families expressed the importance of receiving support from religious leaders in their participation and inclusion within religious communities. Positive experiences were associated with higher rates of inclusion and negative experiences resulted in lower inclusion within these communities (O'Hanlon, 2013). This is further supported by a study exploring the impact of church or religious group involvement on the spiritual health of children. It found that children involved in some church or religious group, on average, experienced a higher self-rated importance of spiritual health compared with their peers who were not involved in any of these activities (Michaelson, Swinton, King, & Pickett, 2020).

It has been suggested that parents may be afraid of the negative reactions to their children with disabilities and, in order to protect them, may keep them isolated from society. This kind of 'protection' leads to isolation of the individuals and has a negative impact on the self-identity and confidence of the person with a disability. Read (2003), as cited in Crabtree (2007), states that negative reactions from the public or the fear of such reactions may cause families to confine their children and themselves to the safer proximity of their homes (Read (2003), as cited in Crabtree, 2007). Some parents might even be embarrassed about having a child with a disability and thus keep their children away from society. It was further found that parents with children with disabilities kept their children from participating in religious

activities as support was not provided. In addition, parents reported that they changed their places of worship because their children were not welcomed or included within religious activities or the congregational centre (Ault, Collins, & Carter, 2013). Stone-MacDonald (2012) carried out a study in an area of Tanzania with the aim of assessing how the local community's understanding of disability impacted on the education of children with disabilities. In this community, it was found that community and family support was very strong. The community, mainly made up of Muslim and Christian believers, had very strong religious beliefs and believed that having a child with a disability was God's plan and it was accepted as that. However, despite this belief, there were instances where it was believed that a child with a disability was a curse and a shame, and some spoke of superstitious beliefs even though they indicated that these were not as prevalent as they had been in the past.

This exclusion on the basis of attitudinal barriers (Goering, 2015) is multi-faceted and persons with disabilities might never have experienced a sense of belonging. Belonging encompasses a relationship which mainly entails positive and long-term attachments with people and places. This happens over time. Being recognised, valued and welcomed is vital for a sense of belonging (Robinson, Hill, Fisher, & Graham, 2020).

While there has been growth in the disability discourse that challenges negative perceptions of disability and persons with disabilities, making disability inclusion an everyday reality remains elusive.

2.5 CONCLUSION

In this chapter, disability inclusion is discussed, framed by the ICF, the medical and social models and the gaps presented within these models. These interpretations are extended through a discussion of colonialism and disability. Literature related to the paucity of focus on religion or theology in relation to disability is critiqued as a limitation in the disability studies discourse. Advocating for the value of including such scholarship within the discipline of disability studies, the researcher reviews literature describing experiences of persons with disabilities and the families of children within various religious communities. In conclusion, the review indicates that there is limited research in this area, in particular, in relation to disability inclusion within the religion of Islam. The opportunity to expand the body of research in this field exists.

CHAPTER THREE: THEORETICAL FRAMEWORK

3.1 INTRODUCTION

This chapter introduces the conceptual framework guiding this thesis. This conceptual framework draws on the Capability Approach (CA) (Sen, 2005), together with perspectives of Ableism (Andrews et al., 2020; Campbell, 2008; Garland-Thomson, 2014; Loja et al., 2013) and De-Coloniality (Grech, 2015; Mashau, 2018; Ndlovu-Gatsheni, 2015).

The first section of the chapter describes disability inclusion from the perspective of the capability approach. It explains how drawing on the Capability Approach can open possibilities to facilitate the inclusion of persons with disabilities within the Ummah, offering a challenge to ableist dominance. The next section describes how a decolonial perspective of disability inclusion offers a way of helping to break down and challenge colonial, dominant and ableist interpretations of disability within the Ummah.

The theoretical perspectives underpinning this study lends to the context of exclusion and disadvantaged experienced by the wider Muslim Ummah as a result of the colonial, apartheid policies of the country as discussed in the literature review (Baderoon, 2019; Joosub & Ebrahim, 2020). Muslims with disabilities were part of this systemic exclusion and may be at risk of forms of exclusion in their own community. The way that disability and disability inclusion is viewed within the Muslim Ummah in South Africa has not yet been researched.

Drawing on the aforementioned theoretical perspectives facilitates the exploration of disability inclusion in the South African Muslim Ummah by looking at the opportunities available for inclusion of persons with disabilities within the community. It seeks to understand disability inclusion through the lens of colonialism and capabilities within the Ummah.

The capability approach (CA) was crafted by Amartya Sen within the field of microeconomics and later been complemented by theoretical developments offered by Martha Nussbaum (Anand, Roope, Culyer, & Smith, 2020; Dubois & Trani, 2009; Robeyns & Byskov, 2020). This approach emphasises that the freedom to achieve well-being is a matter of what people are

able to do and to be, if they have the real opportunities available to them, thus lead the life they are effectively able to lead (Levy & Young, 2020; Robeyns & Byskov, 2020). The core of the CA is to conceptualise the aspect of wellbeing in terms of capabilities and functioning's (Robeyns & Byskov, 2020). Functioning's are 'doings and beings, focusing on activities that a person is able to undertake, that of being well nourished, getting married, education (Robeyns & Byskov, 2020). Capabilities are what are known as the real or substantive opportunities that people have in order to achieve these doings and beings (Robeyns & Byskov, 2020). Saleeby (2007) states that the idea of 'capability' can be seen as useful in being able to understand the opportunity aspect of freedom and human rights and of inclusion. Capabilities are considered real freedoms in the sense that they are corrected for any potential barriers (Robeyns & Byskov, 2020). What are these real freedoms? "Real freedoms" means that one has what is necessary at their disposal to achieve the beings and doings if they so wish to. It is a substantial opportunity not a mere freedom in order to achieve this (Robeyns & Byskov, 2020); the freedom to fully included in their chosen space, for example, to be fully included in the Ummah, with all barriers to inclusion removed. An example could be where a person who is Blind, may have the freedom to get to the Masjid but does not have the substantial opportunity to be full included in the space as there is braille Quran available. Capabilities are, thus, considered real freedoms in the sense that they are corrected for any potential barriers.

The CA expands on the medical and social models to include certain neglected dimensions, namely, a focus on building social connections and on analysing the extent to which the social, cultural and religious dynamics of the context contribute to expanding or impeding choices available to individuals within a community. The CA shifts the focus from the specification of the situation to looking at establishing equality and equity in terms of possibilities and choices (Bakhshi & Trani, 2006). This while, being cognisant that, in most instances, these choices maybe extremely limited (Trani, Bakhshi, Noor, & Mashkoor, 2009). The main characteristic of the capability approach is its focus on what people are able to do and to be (Robeyns, 2005; Sen, 2005). (Saleeby, 2007) states that the capability approach focuses on the life an individual can lead. The CA recognises that the well- being of individuals does not only depend on what they can achieve but also on what options are available for them to choose from.

The analysis of the CA goes beyond categorising, by allowing for the expression of human diversity, freedoms, and choices (Trani et al., 2009). The CA expands on these models to include certain neglected dimensions, namely, a focus on building social connections and on analysing the extent to which the social, cultural and religious dynamics of the context contribute to expanding or impeding choices available to individuals within a community, being cognisant that, in most instances, these choices may be extremely limited (Trani et al., 2009). The capability approach, in contrast to the social model of disability, looks at the human diversity and includes personal characteristics', e.g., race, gender, impairment, something the social model does not explicitly address. The CA allows researchers to analyse the interactions between persons characteristics, resources that are available and the environment where disability may be present (Mitra, 2006). The capability approach does not see the impairment as a 'problem' (medical model) neither does it ignore the individual experience and systemic influences (social model) but it looks at what restricts functioning if the environment does not provide practical opportunities for the individual to function optimally. With its focus on human development, the capability approach addresses various kinds of diversity and thus is relevant to disability (Anand et al., 2020; Norwich, 2014), challenging the ableist rhetoric of striving for the ideal of ability and sameness of individuals within society (Garland-Thomson, 2014).

The CA looks at the human diversity and agency (Robeyns & Byskov, 2020) and includes personal characteristics, e.g., race, gender, impairment, religious diversity. This is a critical element of the CA as many mainstream philosophies often invisibilise the lives of those persons who do not fit the ableist, normative group (Robeyns & Byskov, 2020).

The CA is founded on a broad normative framework designed for the evaluation and assessment of individual well-being and social arrangements and the design of policies; it offers proposals for social change in society (Kimhur, 2020; Robeyns, 2005; Robeyns & Byskov, 2020). It moves away from the income-led economic evaluation methods to focusing on people's ability to achieve the things they value (Dang, 2014; Frediani, 2010).

3.2 DISABILITY INCLUSION FROM THE PERSPECTIVE OF THE CAPABILITY APPROACH

The capability approach has been applied in the disability studies' field (Dubois & Trani, 2009; Mitra, 2018) allowing researchers to analyse the interactions between persons characteristics, resources that are available and the environment where disability may be present (Mitra, 2006). The CA does not see the impairment as a 'problem' (medical model) neither does it ignore the individual experience (social model), but it looks at what restricts functioning if the environment does not provide practical opportunities for the individual to function optimally. With its focus on human development, the CA is relevant to disability as it addresses various kinds of diversity (Anand et al., 2020; Norwich, 2014), thus challenging the ableist rhetoric of striving for the ideal of ability and sameness of individuals within society (Garland-Thomson, 2014). The CA recognises that people are heterogenous in their abilities (Anand et al., 2020). There is, often, this belief that all persons with a similar disability have the same needs.

Capabilities signify the opportunities individuals possess because of their ability or capacity, together with the environment and their life situations (Saleebey, 2007). This moves away from the ableist notion of a 'normative' individual (Bennett & Volpe, 2018; Campbell, 2019) and the need to 'fit' into and conform to mainstream society (Bennett & Volpe, 2018). According to Sen's approach, capability does not just constitute the presence of a mental or physical ability; it is further understood as practical or substantive opportunity as mentioned earlier. A range of options from which a person can choose (Mitra, 2006; Robeyns, 2005). Functioning is what individuals achieve through being or doing, for example, working, resting, being healthy, being literate, being respected and being part of a community (Mitra, 2006; Robeyns, 2005). In other words, the actual achievements of the individual (Mitra, 2006). Functioning is valuable and can be related to well-being (Norwich, 2014). What is critical, is that people have the freedom or valuable opportunities (capabilities) to do what they want, be what they want, in essence, to live the life they would like to live (Mitra, 2018). When they are afforded these substantive opportunities, they are then able to choose between those options that they value and those that they choose not to use (Norwich, 2014; Robeyns, 2005). So, if they want to be part of the community or religion, they should have the option to do this. However, if they choose to be a hermit or atheist, then that is their choice and should be allowed

(Robeyns, 2005). The focus is on the 'beings and doings' that a person values (Bakhshi & Trani, 2006).

The CA further suggests that a person with a disability should not be viewed in terms of what they actually do (functioning) but rather considering the range of possibilities from which they can choose their functioning (capability set). These opportunities must be sustainable rather than just for a limited period of time (Bakhshi & Trani, 2006; Dubois & Trani, 2009). The person should be able to access these range of possibilities whenever they wish to do so.

Disability is then viewed as a denial in respect of the capabilities and functioning's of a person that results from the interaction between personal characteristics (e.g., impairment, income, assets) and the environment (social, political, religious) (Mitra, 2006, 2018). These capabilities, which include practical opportunities, may not be directly observable. In this case, disability arises when a person with a disability is denied opportunities because of an impairment (Mitra, 2006). The CA emphasises the importance of the relationship between the individual and their social groups, together with the institutional factors hindering their choices (Bakhshi & Trani, 2006) within these spaces, in this instance, the Ummah. Full inclusion is an outcome that can be measured through the expansion of people's choices and freedoms within the groups they belong to (Bakhshi & Trani, 2006).

The CA underscores the agency of the individual and how meaningful this agency is within a particular space and whether the individual sees themselves as the key decision-maker within their lives (Trani et al., 2009). This is in contrast to ableist thinking, where the agency of the person with a disability is not afforded the necessary credence and a non-disabled majority wields control over persons with disabilities (Andrews et al., 2020). When this happens the agency of persons with disabilities may be compromised and their experiences, contributions and expectations dismissed, or their voices are muted.

Sen (2005) explains that viewing opportunity in terms of capability, guides attention to adequately distinguish whether individuals are actually able to do the things they value and whether they possess the 'means or instruments or permissions' to pursue what they value

and like to do. This opportunity may also depend on other contingent circumstances (Sen, 2005). For example, if blind people, who are able to read braille, are afforded the opportunity to attend Madrasah (substantive opportunity), where the Quran and other learning tools are available in braille (resource), they have the choice to attend and access Islamic education if they wish to do so (if this is something they value) then this will lead to achieved functioning – where the person is fluent in Quran reading and could even be one who is able to recite the Quran to memory. This aspect links to one of Cobigo et al. (2012) core values of social inclusion, that of full and fair access to personal goods and services.

The capability approach assists in identifying the possibility that two persons may have quite different substantial opportunities even if they have the same set of means (Sen, 2005). For example, a person with a disability with the same income and other ‘primary goods’ as a non-disabled person can do less than the non-disabled person due to not having the same opportunities. Thus, the person with a disability cannot be said to have the same advantages and opportunities as the non-disabled person even if the means or instruments such as wealth, income, primary goods and resources are the same (Sen, 2005). This could relate to two persons using a wheelchair, one a wheelchair user with a permanent disability and another a temporary wheelchair user with a temporary mobility impairment. When they access an ablution facility at a Masjid or prayer room that is not fully accessible to wheelchair users, the long term concerns and impact will be different for the two.

From the perspective of the Capability Approach, Trani, Bakhshi, Bellanca, Biggeri, and Marchetta (2011) argue that it is probably more equitable to compare the performance of people with the way they would have performed in an ‘ideal’ environment designed especially for them with all the barriers removed, rather than within an environment where the individual cannot function optimally. An example is maybe conceptualising a Masjid that would create an environment that would allow full access to persons with disabilities. This could include the provision of braille material or providing a Sign Language Interpreter for Deaf person. Such a Masjid would facilitate for persons with disabilities to fully participate and feel included.

It involves looking at what the person could potentially achieve if barriers were removed, and opportunities were created. The emphasis lies with creating opportunities which result in 'achieved functioning'. In relation to the above example, the potential functioning would be to create the access. If the person has the capability and chooses to make use of the access, the person can achieve functioning for the optimal potential of the individual. Achieved functioning is what a person can access or has the freedom to access if they have the goods, the potential functioning, and the capability to access what they value. This can be achieved when the person with a disability is not undervalued, excluded or expected to fit into a certain societal norm (Goering, 2015; Scullion, 2010).

The CA looks at the full range of the disability experience by not focusing on just the impairment or just the environment. It takes into account the interrelatedness of the individual characteristics, social restrictions and the outcomes measured by expanding people's choices and freedoms (Trani et al., 2011). As Sharma (2005) explains, the hallmark of the capability approach is the focus on capabilities or real opportunities that people have in their lives to achieve things that they can and want to achieve (Sharma, 2005). It aims at fighting the marginalisation and exclusion of persons with disabilities, underpinned by colonial, ableist interpretations of disability, to ensure that persons with disabilities become full participants within society (Buchanan, 2000, as cited in Trani et al., 2011).

The CA framework allows for consideration of what full disability inclusion means. Focus is placed in on the capabilities of the individual with a disability and how they can achieve full inclusion (achieved functioning), in this case when there is the opportunity created for full inclusion within the Ummah. The emphasis of the capability approach is on the interactions between the person's impairment and the context, which consists of stereotypes, prejudice, discrimination and exclusion, policies, and the protocols that are set up to create an environment where there is equality of activity and participation (Bakhshi & Trani, 2006). Sen's Capability Approach maintains that policies should concentrate on what the person is able to do and be, and on removing obstacles facing persons with disabilities so that they can enjoy the freedom to live the life they value (Robeyns, 2005). These obstacles relate not only to physical barriers but the stereotypes, myths and attitudes that pervade society around

disability and persons with disabilities. The Moulana (Priest) of an ideal Masjid could be a person with a disability where the environment is conducive for this to be possible, obstacles should be removed and opportunities available viz, the relevant educational opportunities, addressing attitudinal barriers. There are very few opportunities for persons with disabilities to be trained in the Islamic education field. Policies and processes that guide the Islamic educational space where Moulana's are trained should reflect these opportunities. Mitra (2006) and Trani et al. (2011) assert that this area of policy and implementation regarding disability needs to be given more attention within the disability field. The Muslim Ummah can be assisted to lead the way in this field.

For this study, the capability approach is used to identify the barriers to inclusion within the Ummah, develop an all-encompassing framework to allow the Ummah to identify these barriers to full inclusion, highlighting the impact of an ableist, colonial way of interpreting disability, and put into place a system that will create an environment that allows persons with disabilities to access freedoms and opportunities of their choice, resulting in full inclusion within the Ummah to which they belong. The capability approach allows for a move away from the restricted imposition of the binary positions and expectations of normal/abnormal, able/ unable (Dalkilic & Vadeboncoeur, 2016) to emphasise people's choices and freedoms, personal capabilities and not their deficiencies. The person with a disability would have the choice of how they negotiate within this environment (social, cultural, personal), should the opportunity be available. However, this opportunity has to be created by society and for the purpose of this study society implies the person with the disability, his or her family, the community, and the Priests in the community, in effect, the Ummah. An important element of the capability approach is that the person with a disability participates in the decision-making process. Access to services, quality of life, the social status of the person within the community and, in this case, the Ummah, are dimensions related to the capability approach (Trani et al., 2009).

3.3 DE-COLONIAL PERSPECTIVES

Ndlovu-Gatsheni (2015) introduces de-coloniality as being an epistemological and political movement, advancing de-coloniality as a liberatory language that is necessary for the future

of Africa (Ndlovu-Gatsheni, 2015). De-coloniality arises from the principle that the modern world order is sustained by, not only by the colonial matrices of power, but also by pedagogies and epistemologies that maintain the colonial way of thinking and being (Ndlovu-Gatsheni, 2015). De-coloniality is prefaced on three concepts, namely, Coloniality of Power, Knowledge and Being (Ndlovu-Gatsheni, 2015). These concepts are elaborated on in the discussion chapter.

De-Coloniality is more than just a political tool for resistance. It is also a social movement that allows for spaces in which Black people are able to redefine their identities and reaffirm their humanness (Dei, 2018). For persons with disabilities these social movements may create opportunities to challenge the dominant, pervasive colonial and ableist perceptions around disability. De-colonisation challenges the hierarchical system of the binary and the implications of this entrenched belief system, both within broader society and the Ummah, in particular.

The history of exclusion of Muslims in South Africa during the period of enslavement, in particular in the Cape Colony continued into the racialising laws of Dutch and British imperialists and, later, apartheid (Baderoon, 2014). This meant that persons with disabilities, as part of the Muslim Ummah also experienced such exclusion. As a minority grouping, Muslims were rendered as second class citizens (Vahed, 2010). Over time the focus of discourses shifted to race rather than identifying religion due to apartheid policies (Baderoon, 2014). Members of the Muslim community experienced racism in different forms as a consequence of apartheid policies (Cochrane & Chellan, 2017). For example Muslims were subjected to the Group Areas Act in which they were forcibly removed from their homes and relocated to areas designated for Black and Coloured persons. The restrictions and regulations resulted in direct and indirect hardships in daily life, including imprisonment for many Muslim activists (Cochrane & Chellan, 2017). Muslims with disabilities thus experienced many hardships as result of restrictions that arose from these exclusionary practices.

One of the ways in which the Coloniality of Power was entrenched by the dominant white apartheid government was by refusing to call members of the oppressed groups by their

proper names (Vahed, 2010). Their names were either changed completely or a name given that was easy on the tongue of the colonisers, thus invisibilising the individual. For persons with disabilities within the Muslim Ummah this Coloniality of Power is played out when the person with a disability is not considered 'able' enough to make decisions of their own and not afforded the respect that they deserve as other non-disabled Muslims within the Ummah, especially by the leadership within the Ummah.

Muslims, despite their minority status as a religious group and being part of the minority oppressed group, added their voices to those opposing the apartheid regime and condemned the policies from an Islamic standpoint (Haron, 2006). There were many Muslim activists that were part of the political struggle and post-apartheid, many are members of the democratic government (Vahed, 2010). While Muslims enjoy freedom of religion under the new democratic government, there are isolated incidents where the Muslim community has to fight for their right for religious freedom. One such incident was the court case recently in KZN where there was an objection from a community member to the Call to Prayer (the Adhaan) (Moosa, 2021).

An important element of de-coloniality is the concept of the De-Colonial Turn. In employing the de-colonial turn, it is seen as necessary to understand people's diverse disability experiences. These include multiple expressions of disability culture and further, to recognise that individual pathology must be relocated from inside the individual to the cultural and ecological context (Dirth & Adams, 2019). Adopting a de-colonial turn involves a 'de-colonial attitude', a concept also advanced by Du Bois (Maldonado-Torres, 2007).

A de-colonial attitude stresses the importance of considering the perspectives, points of views, and for this study, the experiences of that group of individuals whose very existence is questioned and considered insignificant (Maldonado-Torres, 2007). This was evident in the experiences of the Muslim community, as part of the oppressed group during the colonial and apartheid years. This also calls for the 'shifting' of the colonial gaze that Baderoon talks about in her (Baderoon, 2014, 2019). A gaze that seeks to dehumanise and delegitimise the "Other"-the colonial subject, which included the Muslim community in SA. It would be interesting to

observe, therefore, how persons with disabilities experience inclusion within the Ummah by the very same Ummah who themselves experienced exclusion and oppression under apartheid rule.

Dirth and Adams (2019) suggest that when approaching inequality (and injustice) in terms of sociocultural affordances, attention shifts away from a focus only on barriers that disable, to highlighting socially constructed privileges and affordances that enable normative activities, viz., human networks, tools and technologies (Dirth & Adams, 2019). This is a systematic understanding of inequality and injustice that highlights that it is important not to dismiss these experiences but to create a space within disability studies discourse for different voices and experiences to be heard (Meekosha, 2011). This draws attention to the way different cultures maintain varied understandings and experiences of disability to make sense of the world.

De-colonisation necessitates discourses that challenge the colonial way of thinking about difference and 'Othering' and for there to be an eradication of the colonial way of being; there is a need for alliances which include both the global South as well as the global North (Grech, 2015), of persons with disabilities as well as non-disabled persons.

De coloniality theory, which has allowed us to engage in critical discourses around the Coloniality of knowledge and Power and has been the impetus for activist movements in recent times, has also elicited some critique. Critique, especially of the early writers on de-colonial theory, has provoked robust discussions on de-colonial theory (Davis, 2021; Hull, 2021). Hull (2021), posits that one of the critiques of decoloniality theory is the rejection of universal truth. An area within the de-coloniality discourse that needs more debate is that of the intersectionality of de-coloniality and disability, broadly, and within Critical Disability Studies. Decolonisation is not a smooth process, it is incomplete (Grech, 2015). Ubisi (2021) states that it is important to understand the implications of coloniality through the perspectives of ableism and the manner in which persons with disabilities have been relegated to the periphery of the colonisers standards of beauty, sexuality and personhood.

This process has to encompass those areas that are still on the periphery of these engagements viz that of disability.

Mashau (2018) further posits that in order for the de-colonial project to succeed; It has to be unshackled from the realm of academic scholars to include voices that have been marginalised. These include faith-based communities. For example, since some Churches were seen to be supportive of racist policies in the past, it is vital for Churches to actively contribute towards creating a non-racial society (Mashau, 2018). The role of the Church and other faith -based organisations should extend not only to create a non- racial society, but one that is non-ableist as well.

The practice of colonial appropriation and the dominant discourse of ableism needs to be highlighted within the Ummah through collective action of all within the Ummah in order to successfully disrupt these methods of thinking and practice.

3.4 CONCLUSION

In this chapter, the researcher discusses the capability approach, a framework that is most suitable for this study as it aligns with the United Nations Convention of the Rights of Disabled People, whose main message is that persons with disabilities are entitled to the full spectrum of human rights and fundamental freedoms without discrimination.

The Capability Approach focuses on human diversity, on the ability of the person with the disability and the freedom to make choices that allows an individual to lead a life one values which can lead to full inclusion, and in the case of this study, the inclusion of persons with disabilities within the Ummah.

The De-Coloniality perspective through the lens of ableism, is selected to complement the capability approach with its relevance in challenging the dominance of the ableist, Colonial narrative within the Ummah is also discussed in this chapter. These perspectives are further discussed in the discussion chapter (Chapter Six).

CHAPTER FOUR: RESEARCH DESIGN AND METHOD

4.1 INTRODUCTION

This chapter focuses on the research design and method applied in this study. It begins with a presentation of the research paradigm and design. A discussion of the value of using the case study method follows. The process of conducting the research is discussed. This includes, the data analysis process used and the ethical principles applied in the study.

4.2 THE RESEARCH PARADIGM

This study adopts a qualitative research methodology. In qualitative research, the aim of the researcher is to focus on exploring, examining and describing people and their natural environments (Babbie & Mouton, 1998; Orb, Eisenhauer, & Wynaden, 2001). There are many different approaches and methods that fall under the category of qualitative research viz. case study, participatory inquiry, ethics, participant observation to name a few (Denzin & Lincoln, 2013; Gray, 2018). Creswell (2007) states that qualitative research is conducted to empower individuals so that their voices are heard and their stories are shared and, in this way, the power relationships that often exist between the participant and the researcher are minimised. The qualitative researcher always attempts to study human action from the point of view of the social actors involved in the study (Babbie & Mouton, 1998). This study provides a space for the participants, especially those with disabilities, to share their experiences of disability inclusion within the Ummah.

The research paradigm used for this study is the interpretive, qualitative research approach (Guba, 1990). Interpretivism and social constructivism are paradigms that are often combined to provide a worldview through which individuals try to make sense of their world, based on their subjective experiences of the external world (Creswell, 2007; Kumatongo & Muzata, 2021). It is the manner in which the person interprets what they have experienced or seen (Kumatongo & Muzata, 2021). Since meaning is viewed as subjective, multiple and varied, the researcher looks at the complexity of the views rather than attempting to reduce meanings into a few ideas. The participants' view of the situations is relied on as their meaning making is prioritised (Creswell, 2007). Interpretivists use methods that enable them to generate qualitative data (Kumatongo & Muzata, 2021) and value transactional knowledge (Denzin &

Lincoln, 2018). Researchers are keenly aware of their own background and positionality in the study (Creswell, 2007).

Prioritising the participants' perspectives is best suited to the current research study as the views of the participants are crucial for adequately responding to the research question. The voices of persons with disabilities offer better insight into the way disability inclusion is understood within the Muslim Ummah in South Africa.

Using the interpretivist paradigm (Creswell, 2007), researchers interpret what they discover, recognising how this may be shaped by their own background and experience (Creswell, 2007). In this study the researcher has explained how her experiences related to disability and in the field of disability (as described in chapter 1) led her to the research question and approach adopted. It is important that the researcher explicitly states her position within the research process and her position within the Muslim Ummah. It is also important that she considers this in relation to the research process. As an activist within the disability field, as well as a woman who is Muslim, she had to be acutely aware of her position within the study process and had to ensure that objectivity was maintained at all times. This is discussed in chapter five.

The researcher's aim is to interpret the understanding or meaning others have of this world (Creswell, 2007).

4.3 THE RESEARCH DESIGN

The qualitative research approach using case studies has been applied in this study. In case study research, the researcher tries hard to understand how the people being studied interpret selected phenomena (Stake, 1995). The researcher seeks to better understand the case, to appreciate its complexity and uniqueness and its interactions with its context (Punch, 2005; Stake, 1995). The case is defined as a phenomenon that occurs in a bounded context (Creswell, 2007; M. B. Miles & Huberman, 1994; Silverman, 2010, 2013). The case is something that the researcher is interested in (Silverman, 2010, 2013).

In the case of an intrinsic case study, the case is of utmost importance and is central to the research (Silverman, 2010; Stake, 1995). The case in this study is that of disability inclusion in the Muslim Ummah. In this research study the intrinsic case study method is utilised.

The intrinsic case study method allows the researcher to learn about a particular phenomenon, in this instance, disability inclusion in the Muslim Ummah in South Africa, specifically in Cape Town, Durban and Johannesburg. It includes all aspects of the Muslim Ummah in South Africa, viz. cultural, social and religious (Stake, 1995). The intention of this study is not to compare disability inclusion across the provinces but to explore how disability inclusion is experienced and interpreted by the different participants within these three cities. It identifies the limitations with regard to disability inclusion, explores the opportunities for inclusion and how best to optimise the opportunities and seeks ways to overcome the limitations and challenges identified by the participants (Flyvbjerg, 2006).

The case study method is a qualitative strategy where the research attempts to explore a program, event, activity or one or more individuals (Creswell, 2007). Data is collected from a variety of data collection procedures over a sustained period of time (Creswell, 2007) and this process can build rich and detailed understanding of the context (Gray, 2018). A significant part of the investigation in this process is the interaction of the unit with its context (Babbie & Mouton, 1998).

There has been robust discussion around the validity of utilising the case study method, with some critics citing a lack of scientific rigour and reliability (Noor, 2008; Takahashi & Araujo, 2020). There is a belief that the case study method is influenced by a bias towards the researchers' pre-conceived ideas and as such has doubtful scientific value (Flyvbjerg, 2006). According to Flyvbjerg (2006), the issue of subjectivism and bias toward verification is something that applies to all methods not just the case study and other qualitative methods.

However, Flyvbjerg (2006) in his in-depth research around case studies concludes that it is a method that holds up well when compared to other methods and that it is a more than adequate method for certain important research tasks in social science. Takahashi and Araujo

(2020) ask researchers to consider the case study method as one way to foster immersion in a phenomenon and contexts. Case studies have the potential to deal with both simple and complex situations and allow the researcher to answer the 'why' and 'how' questions and the influence of the context within which a phenomenon is situated (Baxter & Jack, 2008). The case study method seeks to maintain the integrity and wholeness of the case (Silverman, 2010).

The boundaries of the current case are framed as consisting of members of the Muslim Ummah who have had either personal or indirect experiences of disability inclusion within religious spaces, including accessing Islamic education and within the social spaces.

4.4 SELECTION OF PARTICIPANTS

The participants for the study were selected using purposive sampling. Purposive sampling enables the researcher to selectively recruit participants based on specific criteria that align with the research question, aim and purpose (Tashakkori & Teddlie, 2003). In this study, purposive sampling enabled the selection of individuals and sites for their potential to inform and provide insights into the research problem articulated (Creswell, 2007). Four groups of participants, all of whom identify themselves as Muslim, were selected:

- Adults with different physical and sensory disabilities;
- A family member of participants with disabilities;
- A group of Ulema within the Muslim Ummah;
- A group of non-disabled persons within the Ummah.

The following section provides details about the inclusion criteria applied to participant selection:

4.4.1 Participants with disabilities

Persons with disabilities are central to the study as they are living the experience of disability inclusion within the Muslim Ummah and are best positioned to contribute to this exploration. The following inclusion criteria were used to select persons with disabilities to participate in this study:

- Self-identified Muslims. Any adult individual who identified him- or herself as a practising Muslim was eligible to participate in the study, as the specific focus of the study was on the Muslim Ummah.
- Persons with Disabilities who either had a physical impairment, visual impairment or were blind or who had a hearing impairment or were Deaf. While there are no aggregated disability statistics according to religious affiliation, the statistics available indicate that of the 7.5 % of persons with disabilities in South Africa, approximately 11% are persons with a visual impairment, 3.6 % with a hearing impairment and 3.5 % with a mobility impairment (Statistics South Africa, 2011). While the medical model is critiqued in the Literature Review (2.1 FRAMING DISABILITY INCLUSION, pg. 14 – 16) (Bennett & Volpe, 2018; Hinojosa, 2018; Retief & Letšosa, 2018), the medical model perspective is necessary in identifying the impairment. This is consistent with the definition of disability adopted in this thesis which is based on the UN Convention of the rights with persons with disabilities. Thus, the use of the model is for the identification of an individual's impairment and is not used to define the potential participant.
- Limiting the inclusion criteria in this way aligns with the study's exploratory nature. It also assists with managing the scope of the study by taking into account the researcher's capacity and time constraints. While including persons with neurocognitive or psychiatric impairments would have enriched the study, it would have put additional demands on the way that the study was managed. The researcher did not have the capacity to provide for adequate screening of persons with neurocognitive or psychiatric impairments. This would have added to the scope of the research which was beyond the researcher's capacity to implement. The limitations presented may have impacted on the quality of the data generated. Future studies could include other disabilities not included in this initial study, as well as children with disabilities.

4.4.2 Families of persons with disabilities within the Muslim Ummah

Family members of persons with disabilities are also impacted when it comes to inclusion within the Ummah. Families of persons with disabilities play a significant role in the everyday experience and understanding of their family members with a disability with regard to disability inclusion. Their experience provides rich data for the study. The selection of the

family members was directed by the participants with a disability. Participants identified the family member who, in their view, could provide insight into disability inclusion. Anyone they considered a family member was eligible.

4.4.3 Ulema within the Muslim Ummah

The Ulema is a body of Muslim scholars recognised as having specialised knowledge of Islamic sacred law and theology.

The Ulema play a critical role within the Muslim Ummah. They are respected senior members, providing guidance and leadership to the rest of the Ummah. Their knowledge and understanding offers insight into the frame of reference of the Muslim leadership's understanding of disability inclusion. Their awareness can facilitate full disability inclusion within the Ummah. The criteria for selecting Ulema is that they are prominent members of the Ummah, contributing to leadership within the Ummah and thus having the capacity and position to influence disability inclusion within the Ummah. The Ulema might, for example, be an Imam (Head Priest) of a Masjid in a community or a Sheikh (Priest).

4.4.4 Non-disabled persons within the Muslim Ummah

A non-disabled person is someone that does not identify as someone with a disability. It is important to hear from non-disabled persons within the Ummah as they play an important part in ensuring disability inclusion and it is meaningful to obtain a wide range of views on the interpretation of disability inclusion. They are part of the Ummah and might share responsibility to effect change; thus they are a significant group of participants.

4.4.5 Sample Size

To ensure that the sample size was manageable, participants selected were from the 3 major cities in South Africa, Durban, Johannesburg and Cape Town. Participants were selected from these 3 cities in order to obtain a wide range of views on disability inclusion from within South Africa.

The figure below represents the number of participants per city who participated in the study:

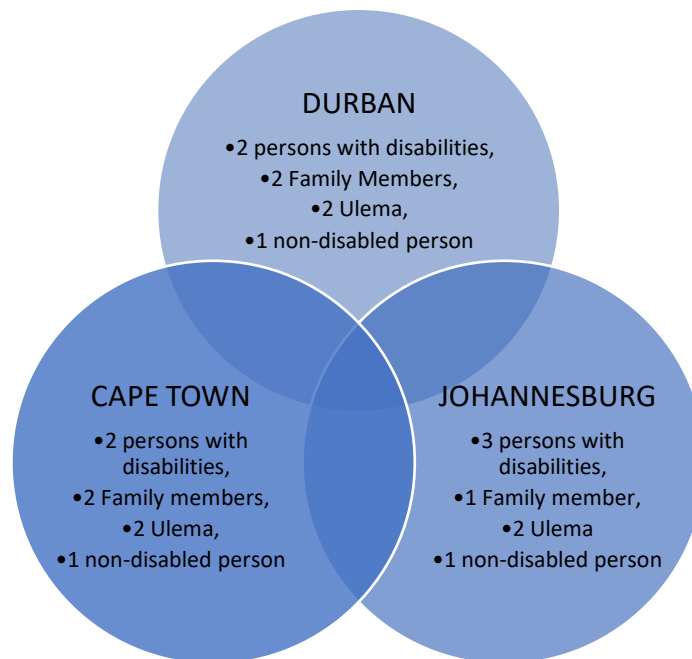


Figure 4. 1:The above figure indicates the breakdown of participants per city

The researcher had planned to recruit two participants with disabilities, two members of the Ulema, two family members of the participants and one non-disabled member of the community. However, she experienced difficulty in securing interviews with family members of two of the participants with disabilities residing in Johannesburg and decided that one additional participant with disability and a family member should be included in the study.

Seven persons with disabilities, five family members, six Ulema and three non-disabled individuals participated in the study, in total 21 participants.

4.4.6 Recruitment

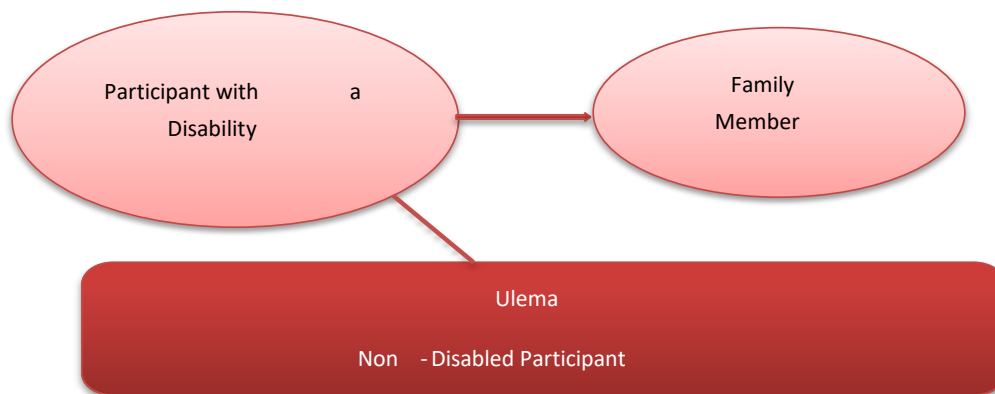


Figure 4. 2: Represents the unfolding of the interview process i.e. participants with a disability directed the researcher to a family member to be interviewed

Figure 4.2 : Represents the unfolding of the interview process i.e., participants with a disability directed the researcher to a family member to be interviewed. They also suggested an Ulema in their community. The non-disabled participant was a referral from the participant with a disability or someone from the community not connected to the participant with a disability.

The researcher had been working in the field of disability for a number of years, had vast experience in this field and was very familiar with it, so it was important that she ensured that she maintained objectivity during the research process and thus she approached a renowned disability activist within the Muslim Ummah who first directed her to participants who met the criteria of the study. The snowballing method was then used to select subsequent participants.

Once the participants were identified, they were contacted telephonically for the researcher to introduce herself, explain the study and to enquire whether they would be interested in participating. This process started once Ethics clearance was received in January 2017. Each identified participant received a letter that provided further information ([Appendix A](#)) so that they had access to a detailed explanation of the study. All identified persons were invited to confirm their participation once they had read the information letter. Once confirmation was

received, the researcher arranged for the interviews to take place at a time and place most suitable to the participants.

In one of the cities, the researcher approached the main theological body to secure an interview with one of the Ulema. This is a leading theological body in South Africa and their Ulema are well known within the Ummah. After explaining the study to them, the Head agreed to be interviewed. The researcher travelled to the city to conduct the interview but the interview did not take place as the participant did not keep to the arrangement. Contact was made with the organisation on numerous occasions, with the administrative assistant making a great effort to arrange an interview for the researcher, with any of the Ulema within the organisation that might be available to meet if the Head was not available. However, this did not materialise. The researcher was then directed by one of the participants to a different Ulema from the community who was willing to be part of the study.

The non-disabled participants were selected based on convenience. They were either suggested by one of the participants with disabilities or they were individuals who the researcher knew had some involvement in the field of disability. Those who participated in the study were willing and were accessible to the researcher.

The following table explains the number of participants who were part of the study:

All participants have been given pseudonyms.

Table 4. 1: Participants with Disabilities

| NAME | AGE | IMPAIRMENT | GENDER | CITY |
|-------------|----------------------|--|---------------|--------------|
| RIYADH | 28 | QUADRIPLÉGIC Acquired disability later in life | MALE | CAPE TOWN |
| DILSHAD | Did not indicate age | MOBILITY IMPAIRED Born with a disability | FEMALE | CAPE TOWN |
| IMRAN | 63 | PARAPLEGIC Acquired disability later in life | MALE | DURBAN |
| SAFIRA | 58 | BLIND Born with a disability | FEMALE | DURBAN |
| AYESHA | Did not indicate age | DEAF Born with a disability Ayesha used a Professional Sign Language Interpreter during the interview. Someone whom she uses all the time and is comfortable with. | FEMALE | JOHANNESBURG |
| ISMAIL | Did not indicate age | DEAF Acquired disability when he was very young. Ismail's daughter Tasneem interpreted for him. She usually interprets for him, even though she is not a qualified Sign Language Interpreter, She did not interpret in the first person. | MALE | JOHANNESBURG |
| ASHRAF | 53 | PARAPLEGIC Acquired disability later in life | MALE | JOHANNESBURG |

Table 4. 2: Family of Persons With Disabilities

| NAME | RELATIONSHIP | CITY |
|-------------|---------------------|--------------|
| TASNEEM | DAUGHTER OF ISMAIL | JOHANNESBURG |
| RAFIYA | SISTER OF SAFIRA | DURBAN |
| NOORI | WIFE OF IMRAN | DURBAN |
| ASLAM | FATHER OF RIYADH | CAPE TOWN |
| FAZILA | MOTHER OF DILSHAD | CAPE TOWN |

Table 4. 3: The Ulema

| NAME | CITY |
|-----------------|--------------|
| IMAM SALEH | CAPE TOWN |
| SHEIK LUQMAN | CAPE TOWN |
| MOULANA RASHID | JOHANNESBURG |
| HASSAN | JOHANNESBURG |
| MUFTI BILAL | DURBAN |
| MOULANA MOHAMED | DURBAN |

Table 4. 4: Non-Disabled Participants

| NAME | CITY |
|-------------|--------------|
| YASIN | DURBAN |
| HUMAIRA | JOHANNESBURG |
| SARAH | CAPE TOWN |

4.5 DATA COLLECTION METHODS

The researcher initially envisaged utilising a number of methods of data collection for the study, viz. interviews, visual images (photographs) and document reviews. The value of obtaining data from different sources is that the researcher is able to provide an understanding of the phenomenon being studied in a more holistic manner (Baxter & Jack, 2008). However, the researcher experienced challenges in employing this set of data generating methods and had to change track, while still obtaining data using several methods. The several methods that the researcher applied included interviews with different sets of participants and document reviews. As a result of the challenges experienced in securing follow-up interviews from the different sources, the researcher decided only to use the data from the initial interview, which in itself provided rich data for the study. A total of twenty two (22) interviews were held. Obtaining documents from the Masjid proved difficult and the researcher then decided to review three Muslim publications to explore whether the issue of disability inclusion was raised in any of these publications. With difficulties experienced in the participants following up with the taking of the photographs, the researcher decided to use the set of photographs taken by Ashraf prior to the study since they provided powerful and rich data for the study.

These challenges are elaborated in this chapter.

4.5.1 Interviews

Punch (2005) states that interviews are one of the most 'powerful' ways in which we can understand others (Punch, 2005). They allow the researcher to access people's perceptions, meanings and definitions of situations and constructions of reality (Babbie & Mouton, 1998). The in-depth interview method was used to gather data. According to Stake (1995), the interview is the main path to multiple realities. The interviews allowed participants space to talk about their experiences of disability inclusion within the Ummah. The participants were aware that this was a safe space and that the information would be treated with confidentiality and so they were able to share their deep, intimate experiences with the researcher.

DiCicco-Bloom and Crabtree (2006) explain that in-depth interviews elicit detailed narratives and stories of the interviewees. The interview is a personal and intimate discussion and the

questions asked are open, direct and verbal. It is important that the interviewer has a clear advance plan. The interviewer should arrive with a set of questions worked out in advance; however, there may be a departure from the protocol, which should be limited by design (Stake, 1995).

The interview process started in May 2017 and ended in early 2019. An initial interview was held with each participant (that is, each participant with a disability, each ulema and each non-disabled participant) after obtaining informed consent from the participants ([Appendix D](#)). During the initial interview with the participants with a disability, they were asked to capture images by taking photographs of what they perceived to depict disability inclusion and exclusion and a follow up interview was held to discuss the images captured. The use of visual images, in the form of photographs, is a way to represent or understand people's lives and their environments (Prosser, 1998) and researchers have begun to realise the value of using visual approaches in research studies (Drew & Guillemin, 2014).

Although all the participants with disabilities agreed to take the photographs, none of them followed through with this request. After a number of requests for the photographs to be shared, the researcher decided not to pursue this method of data collection. There was only one participant with whom the researcher was able to secure a follow-up interview but the photographs he shared were ones that he had taken prior to the study. There were nine that were taken and three were utilised for this study. These photographs are discussed in the findings chapter.

All interviews were audio recorded, allowing the researcher to focus on the participant and to think more clearly, probe more deeply and to reflect during the interview process (Stake, 1995). Shorthand field notes were also taken, adding an important element to the recording of the interview.

4.5.2 Document Review

Stake (1995), states that reviewing documents when gathering data is similar to observations and interviews. During the interviews with the Ulema, the researcher requested access to

relevant Masjid documentation, viz. policies, standard operating procedures and minutes of meetings over the last five years. The aim of obtaining and reviewing these documents was to assess whether deliberations happened within Masjid proceedings related to creating inclusion for persons with disabilities. The intention was to gauge what was happening and to identify possible gaps. However, the researcher experienced difficulty in obtaining these documents in that the documents were not forthcoming or publicly available. It became apparent that many decisions were made through discussion without documentation. She then decided to review three major Muslim publications instead to gain insight into the Muslim media's focus on issues of disability inclusion. A total of 108 articles from the three Muslim publications, namely Muslim Views, the Majlis and the Al Qalam were reviewed. Each newspaper has a monthly publication. These three publications were selected as they are widely read within the Ummah and report on issues relevant within the Ummah. Upon review, no content focusing on disability or disability inclusion was found in these publications. One article in the Majlis described the problem with the manner in which shoes were scattered within the place in the Masjid. Although the article does not mention how this might impact on persons with disabilities and disability inclusion, the relevance of this information of the article is raised in the findings chapter.

4.6 DATA GENERATION PROCESS

4.6.1 The Interview

Data was collected from persons with disabilities, a selected family member, the Ulema and non-disabled persons to understand the case of disability inclusion. The interviews were held at a time and place that was suitable for each of the participants.

4.6.2 Participants with Disabilities

In-depth individual interviews were held with each participant. The researcher was cognisant of the fact that the participants were taking time off from their busy schedules and so it was decided that the interviews would last for approximately an hour. However, there were instances when the participants were so engrossed in sharing their stories that the interview lasted longer. Four open-ended questions guided the interviews with the participants with disabilities (Appendix E). These open-ended questions provided the participant with the space

to talk about their interpretation and experiences of disability inclusion within the Ummah and how this had impacted on their lives as a person with a disability. The researcher requested permission from the participants to audio record the interviews.

The researcher was very sensitive to the fact that the topic under discussion was one that might bring up many emotionally laden issues for many of the participants with disabilities and so she ensured that participants felt comfortable to share their experiences with her, that they felt safe. She explained to the participants that all that was discussed during the interview process would be handled with confidentiality and that pseudonyms would be used to identify the different participants. She introduced herself and explained the research study to the participants and engaged in casual talk with them before proceeding with the formal interview process. As explained earlier, the interviews were held at a time and place that was suitable for the participant, either at their home or place of work or study.

Although the researcher had a prepared interview schedule ([Appendix E](#)) and kept to these questions, she also picked up on points that were brought up by the participants, identified nuances and probed further when necessary. Notwithstanding the fact that the interviews were audio recorded, she made her own field notes on key points and observations during the interviews which she cross referenced with the transcriptions.

The experience of persons with disabilities is vital to understanding the case of disability inclusion and for this reason participants were given space to talk in depth of their experiences around disability inclusion. The data collected from each person with a disability also informed the questions posed to the other participants.

After the initial interview, the participant was asked to capture images (photographs) that portrayed their experiences of disability inclusion/exclusion – images (photographs) where there was either inclusion or exclusion of persons with disabilities; these would inform the second interview. During the second interview, the intention was to ask the participants to speak to the images captured by them and link this to the discussion from their first interview. The researcher was aware that the Blind participant would not be able to take the

photographs and this data collection method was discussed with her and she was asked about the best way to proceed. She suggested that she ask a family member to take the photographs for her. She was comfortable with this alternative option. The researcher is aware that this could be seen as a limitation.

Despite all the participants having agreed to capture the images and being reminded on a number of occasions to take the photographs, getting them to capture these images posed a challenge. The researcher was only able to secure a follow-up interview with Ashraf with images he had taken prior to the initiation of the research study and these images were used in the follow-up interview. After having reminded the other participants to capture the images on a number of occasions, the researcher decided to proceed with the research process without the images and the second interview. Even though the participants had agreed to take the photographs, it was not something she could enforce. Their not following through with the images might have been as a result of their work and personal commitments and their being unable to find time to capture the images or fit in another interview in their busy schedules. It might also have been that the initial interview was an emotional experience which they may not have wanted to go through again. The data obtained from the initial interviews provided rich data that spoke to the research question and the objectives of the study.

At the commencement of the study, the researcher was a bit apprehensive that the selected participants might have been reluctant to be part of the study. However, she was pleasantly surprised that all the participants with disabilities were very willing to be participants and were very open in sharing their experiences of disability inclusion within the Ummah. The data obtained from this group of participants is very rich and she felt privileged that they trusted her with their personal experiences of being a person with a disability within the Muslim Ummah.

One of the challenges experienced with the two participants residing in Johannesburg was gaining access to a family member. Both the participants interviewed were very willing for a family member to be interviewed. However, a number of requests were made to be

introduced to the family member but this did not materialise and the researcher stopped pursuing this. She assumed that they might have reasons for not arranging the interview and respected their position. She then decided to interview an additional participant with a disability in Johannesburg and was able to interview a family member of that participant.

4.6.3 Interviews with Family Members of Participants with Disabilities

In depth, face-to-face, open-ended interviews were held with this group of participants. Participants were asked to speak about their experiences of disability inclusion and to add depth to the issues that were raised in the interviews with the participants with a disability. Family members were very forthcoming in sharing their experiences of being a family member of someone with a disability and how this plays out in the Ummah and the impact this has had on them as a family.

4.6.4 Interview with the Ulema

In-depth, face-to-face interviews were held with the Ulema.

The Ulema were given an opportunity to talk about disability inclusion, how they interpreted disability inclusion and the way in which this was being implemented in their religious spaces. This is an area that might have created some discomfort for many people and in order that the discussions were open and frank, the researcher assured the Ulema that this was a safe space and that confidentiality and anonymity would be maintained. The Ulema were honest and upfront in discussing the way they had engaged with creating spaces that were inclusive or not for persons with disabilities within the Ummah.

During the interviews, the Ulema were asked whether the researcher would be able to access any Masjid documents such as policies, standard operating procedures or minutes of meetings for the last 5 years, to see what deliberations had taken place around disability inclusion - if any. All the Ulema were quite open to this idea, however, they all indicated that there were no formal minutes of their meetings and that if notes had been taken, these had not been presented in any formal manner. It became apparent that this method of data

collection would not yield the desired results and that the researcher had to find a different method of obtaining the data. This is discussed further in the findings chapter.

The researcher had feared that she might experience some difficulty when approaching the Ulema, being a woman, because in Islam, there has to be separation between males and females who are not siblings or close family members and the Ulema are very particular about that. To manage this, there was always someone else present during the interview, either the wife, daughter or a staff member; this satisfied the Islamic law. While the person was always present in the same room but was in close proximity, the researcher always ensured that confidentiality was maintained and no names of other participants were mentioned in the interviews. She also feared that there might be some reluctance to be interviewed as the study area is one that the Ulema do not generally focus on in their discourse around Islamic matters in the Masjids. She was very pleased when she did not encounter any struggle in approaching this group of participants. Even though she struggled in securing the interview with the theological body, when she initially approached them and introduced the topic, they were willing to be interviewed.

4.6.5 Interview with a non-disabled person

In-depth, face-to face-interviews were held with the non-disabled participants. This group of participants were asked to share their experiences of disability and disability inclusion, their interpretations and the associated challenges.

During the interview process, the researcher assured the participants that their confidentiality would be preserved and that the privacy of the person was protected.

4.6.6 My reflections during the time of interviewing:

As I embarked on this PhD journey, I was very nervous as I saw this as a very daunting task. There were many a time when I would ask myself whether I was up to this journey but I persevered because the more I engaged with my participants with disabilities, the more I realised how important my research study was. I anticipated that I might have some challenges in gaining access to some of my participants, in particular the Ulema (Priests) but

I was pleasantly surprised that most of the participants were open to participate in the study and share their experiences.

As the study locations spanned the 3 major cities viz Durban, Johannesburg and Cape Town, there were times where I experienced challenges as I had to travel to a particular city and was unable to gain access to the participants. One such experience was with the Ulema in Johannesburg. While the head Moulana (Priest) was initially very willing to participate in the study, subsequent attempts to arrange an interview with him were unsuccessful due to his work commitments, even though I had travelled to Johannesburg for the interview. I was very disappointed but also quite distressed. Not just because he had agreed to be interviewed and this did not materialise, but also I viewed it as him not taking the matter seriously, perhaps relegating persons with disabilities to the side lines. There was also an element of anger within me. I know that as a researcher, I had to be fair and not allow my emotions to lead me. Doing that was not always easy especially as I listened to the deeply emotional accounts of participants with disabilities. While I may have experienced, this set back with the certain Ulema, the positive experience with others helped me realise that all was not lost, that there are those Ulema that do see this as an important area that needs attention.

Not being able to get the second interviews and the images from most of the participants also created some frustration for me. However, I respected the process and accepted that there might have been many reasons for this and I respected the participants non- response.

Listening to the experiences of the participants with disabilities and their families had an emotional impact on me. After each interview with a participant with a disability, I needed to take a step back and take time to process what I had been told and what I understood. I had to be conscious of remaining open to understanding the phenomena in its complexity. To enable me to do this I also held regular reflection and debriefing sessions with my supervisors and colleagues. This helped me to continue with the study in an open and fair manner. At times it felt like an incredibly lonely and difficult journey. However, in those dark and difficult times, what kept me going were the stories that the participants with disabilities shared with me. I know that, for many, it was extremely difficult to open up, reflect upon and share their

experiences. Listening to the stories also led me to question the role I may have played in contributing to the kinds of experiences that participants with disabilities shared. How complicit had I been in the exclusion of persons with disabilities that had been allowed to prevail within the Ummah? I know that all participants placed their trust in me to take what they shared and to do something about it. In Arabic, the word 'Amanah' means trust and it involves trusting someone to fulfil a responsibility. I am very aware that I have to fulfil the 'Amanah' given to me by participants.

Finally, this led to again reflecting on my earlier experience working in the Disability Units at both the University of Kwa-Zulu Natal and the University of Cape Town where I worked with the Muslim Students' Association to promote the access and inclusion of Muslim students with disabilities. We achieved some changes, but more was needed. On a visit to the University of Cape Town close to the conclusion of my data collection I visited the Muslim prayer facility to see if the changes that I, together with the Muslim Students' Association, had advocated for had been made. I found the area to remain totally inaccessible (see photos: Appendix H). I was left thinking that everyone was accountable for this situation and I included myself in this. The slow process of completing a PhD impacts on taking this piece of work forward and working harder to advocate for and or implement change. I am committed to making the voices of my participants, especially those with disabilities and of their families, heard.

4.6.7. Document Review

As mentioned earlier, during the interview with the Ulema, the researcher requested Masjid documents and while the Ulema were quite open to this idea, they all indicated that there were no formal minutes of their meetings and if there were notes taken, they were not presented in any formal manner. The researcher realised that this data collection method would not be feasible and changed track. Instead, she reviewed three Muslim publications, viz. the Al Qalaam, The Majlis and The Muslim Views. The review period of the publications was from 2015 to 2018 in order to review the most current articles that might have focused on disability inclusion within the Ummah. She searched these publications for any references to disability inclusion in any part of the publication.

4.7 DATA MANAGEMENT AND ANALYSIS

4.7.1 Data Management

All data was kept in a secure place that was only accessible to the researcher. All documentation was filed and kept in a secure space in the researcher's home to which only she had access. Different kinds of data emerged from the different data sources, viz. interviews and publication reviews, as well as the photographs provided by Ashraf. Data also emerged from events that did not happen, namely, the numerous efforts to contact the Priests in Johannesburg. Data will be stored for five years and destroyed thereafter.

4.7.2 The Data Analysis Process

The richness and complexity of qualitative research means that there are different methods of analysing the social reality being studied (Punch, 2005). Analysis is the way in which meaning is given to first impressions as well as to the final compilation. "It means taking something apart" (Stake, 1995, p. 71). Researchers reach new meanings about cases in two strategic ways: "through direct interpretation of the individual instances and through aggregation of instances until something can be said about them as a class" (Stake, 1995, p. 74). For this study, both these methods of data analysis were used.

Stake (1995) goes on to say that significant meaning comes from the re-emergence of a pattern over and over. Very often the patterns are known in advance; they are drawn from the research questions. The research questions guide the analysis (Stake, 1995). The researcher selects those instances that are most revealing, identifies vignettes and from there composes the narratives for the final presentation (Bresler & Stake, 1992). Data analysis methods need to be systematic, disciplined and transparent (Punch, 2005).

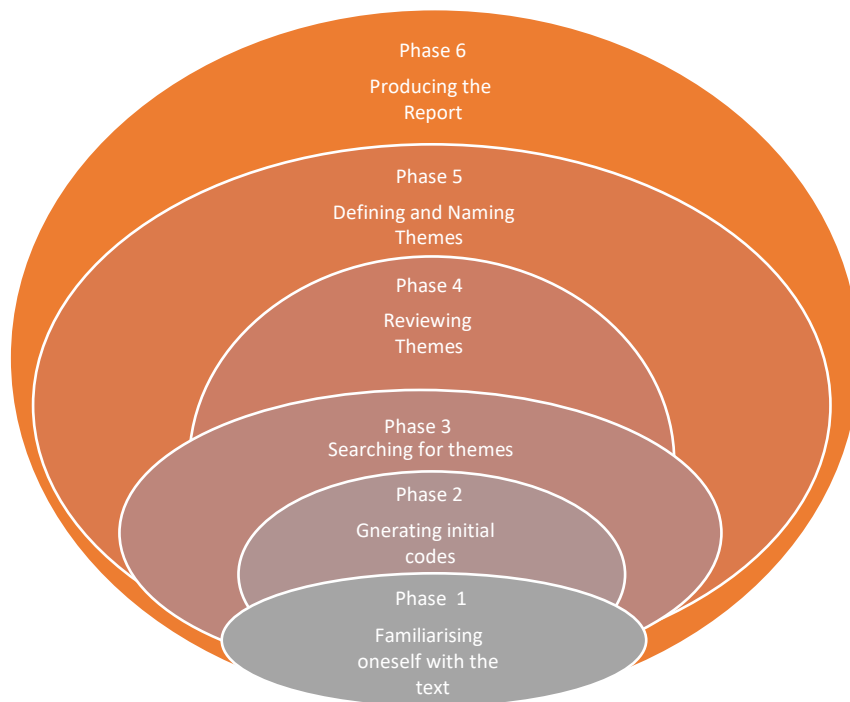


Figure 4. 3: The Data Analysis Process (Braun & Clarke, 2006)

Data analysis was ongoing throughout the data gathering process as suggested by the view that there is no one particular moment when data analysis starts (Stake, 1995). Data analysis ended when the researcher had a clear picture of the interpretation and experience of disability inclusion within the Muslim Ummah. This stage happens when ‘we come to understand the case’ and some sense has been made of the case being studied (Stake, 1995, p. 77). Data analysis ends when saturation is reached and the researcher is able to answer the research question. The data analysis process ended in early 2020 and the writing up of the report began.

For this study, after each interview was completed, the researcher listened to the audio version of the interview to familiarise herself with the data. The interview was then transcribed verbatim. Once the researcher received the transcribed version, she then checked the transcribed data with the audio recording to ensure accuracy. The data was then cleaned up. Braun and Clarke (2006) state that it is vital that researchers immerse themselves in the data so that they are become familiar with the depth and breadth of the content. Reading and re-reading the data helped the current researcher gain a deep understanding of the data.

Each transcript was coded. Coding is a process where certain items of the text, which appear interesting to the researcher, are attached to meaningful labels or codes (Babbie & Mouton, 1998; Braun & Clarke, 2006). Units of meaning are identified, grouped and assigned codes. During this phase, it is important to ensure that the codes speak to the research question and the objectives of the study. Units of data were noted within each particular emerging theme. The researcher then grouped the codes under a particular category. Patterns were sought within the data to find a link within the different categories. In this phase, the researcher analyses the way the different codes form an overarching theme (Braun & Clarke, 2006). The researcher looked for the themes that emerged from all the data and coded them accordingly to answer the research question. Thereafter, themes were examined for any relationship between categories. Themes were established and coded accordingly (Drew & Guillemin, 2014). The 'keyness' of a theme is established when it captures what is valuable in relation to the overall research question (Braun & Clarke, 2006). The publications were also reviewed to establish whether there was any mention or discussion around disability inclusion and they were coded accordingly. The codes were analysed to identify emerging themes from each data set.

The data emerging from each of the data sources was analysed using the research question as a lens to guide the analysis. Each data set was analysed to identify categories and themes that reflected full inclusion within the Ummah and to look for areas where limitations to opportunities for full inclusion were experienced.

Thereafter, the categories emerging from each data set were cross analysed. As the researcher began to synthesise what emerged from the data sources across the data sets, she discussed this with her supervisors. These discussions informed the ongoing data analysis. Themes were refined and renamed if required. Of paramount importance was the skill and expertise of the researcher in engaging in this process of refining (Drew & Guillemin, 2014). Once she and her supervisors were satisfied that there was thorough engagement with the data and were in agreement that the themes identified answered the research question and objectives, themes were finalised and the process of writing up the report of the findings

began. The process of writing up the report began in early 2020 and the Thesis handed in for examination in November 2020.

4.7.3 Conclusion

Although it was planned that several methods of data generation would be utilised to gather data, the researcher encountered challenges in getting participants with disabilities to capture images of their experiences of disability inclusion/exclusion. As mentioned earlier, all the participants with disabilities were agreeable to capturing these images and asked to be reminded to do so, which happened; however, they did not follow through with image capturing. The researcher had to respect that this might have been a difficult task and therefore decided to set aside this method of data collection for all participants except Ashraf who did follow through with the captured images.

The initial plan for reviewing Masjid documents also proved challenging. The findings are discussed in the next section. However, the data obtained from the interviews proved to be very rich data responding to the research question and objectives.

4.8 ENSURING RIGOUR AND TRUSTWORTHINESS

There have been many debates about the processes used to ensure rigour in qualitative research. The traditional concepts that play an important role in ensuring rigour in research are reliability and validity. However, there are many differing opinions about whether they are relevant to qualitative research. The concepts relevant to this research are credibility, transferability, dependability and confirmability. These 'protocols' form part of the triangulation process which ensures the rigour and trustworthiness of the study.

4.8.1 Credibility

Babbie & Mouton refer to credibility as the “compatibility between constructed realities that exist in the minds of the respondents and those that are attributed to them” (Babbie & Mouton, 1998). Credibility deals with the question of how consistent the findings are with reality (Merriam, 1998). Lincoln and Guba (1985) stress that credibility is critical in ensuring trustworthiness. Member checking, where the participants review the material for accuracy and to ensure that they agree with the account that had been captured (Stake, 1995) was

utilised to ensure credibility. This also helped to triangulate the researcher's observations and interpretations. The themes of study were presented to the participants. This ensured rigour.

Furthermore, the findings will also be presented to the wider Ulema body and at a seminar open to the community. It is important to build the trust of the participants by being open and honest about the research process and findings.

4.8.2 Transferability

Transferability is when the findings from one context can be applied to other contexts or respondents (Babbie & Mouton, 1998). Lincoln and Guba (1985) state that it is the responsibility of the researcher to ensure that adequate information from the field is provided for there to be the possibility of a transfer (Shenton, 2004). This has been achieved by providing a thick description (Shenton, 2004) of the process, spaces and places where this research took place so that others can consider its applicability to their contexts. The findings of this study are not only applicable within the Muslim Ummah but there are aspects of the study that may be relevant to different faiths.

4.8.3 Dependability

Dependability is about ensuring that proper research practices have been followed. The process of the study should be reported in detail so that any future researcher can repeat the work (Shenton, 2004). In the current study, extensive detail about the research process and participant selection and participation is provided to ensure dependability.

4.8.4 Confirmability

Steps were taken to ensure that the results of the study reflect the experiences and ideas of the participants and not those of the researcher (Shenton, 2004). Triangulation plays an important role in this process and helps reduce researcher bias (Shenton, 2004). With triangulation, evidence is collected from multiple sources to corroborate or confirm the same fact or finding (Rowley, 2002). In this study, triangulation was enhanced through multiple sources of data generation and across three cities in the country. In order to ensure accuracy and find alternative explanations, the researcher followed the same procedures with all participants (Stake, 1995).

Debriefing was carried out with the supervisors and a neutral person. This took place through regular discussions and sharing the researcher's reflective research journal. The discussions with the neutral person were either face to-face or using one of the online platforms available. These interactions allowed the researcher to engage more deeply with the data, ensuring that she represented the experiences of the participants accurately.

4.9 ETHICAL CONSIDERATIONS

Ethical approval to carry out the research was sought and received from the Human Research Ethics Committee of the Health Sciences Faculty (HREC NO: 545/2016). The ethical practices applied in this study are in line with the Helsinki Declaration. The following ethical principles were applied in this study:

4.9.1 Autonomy

The principle of autonomy implies that participants may exercise their rights to either accept or refuse to participate in the study voluntarily. The participants have the right to be informed about the study and to participate only if they choose to. This is known as informed consent (Orb et al., 2001). Informed consent involves negotiating trust and has to be continuously renegotiated (Orb et al., 2001). Participants were given information about the study and asked to give their consent to participate (See Appendices C & D). When the participants did not follow through by providing the photographs as requested, the researcher respected their decision thus reflecting her respect for their autonomy in this process. In advising potential participants about the risks and benefits of being part of the study, she ensured that the information shared was accurate and that they were free from coercion.

The participants were also informed that they had the freedom to choose to be part of the study and could withdraw at any stage during the research process with no negative consequences (Orb et al., 2001).

4.9.2 Beneficence

Maintaining the principle of beneficence means doing good for others as a priority in order to prevent harm. The main risk in this study was the risk of having to reveal participants'

identities if criminal activities were to be uncovered. The consent form indicated that, in such instances, the researcher was obliged to report such activities to the relevant authorities. It is the responsibility of the researcher to ensure that the participants were not compromised in any way (Orb et al., 2001). Fortunately, this was not necessary during the study. Pseudonyms were used to ensure that the identities of the participants were not compromised. This was especially important when issues raised in the interviews with persons with disabilities were brought into the interview with a family member and the Ulema. The researcher ensured that the issues raised were kept confidential and were raised in a manner that did not expose the person with a disability. Furthermore, the issues discussed were those related to disability inclusion and not personal or interpersonal issues. The researcher respected the right of the participants when instances arose where they preferred to refrain from direct discussion of certain issues. She remained alert to this and noticed that in all instances where the participants chose not to answer questions directly, their responses or discussion of such issues were woven into other parts of the interviews.

The participants' voices were heard, giving them an opportunity to talk about disability inclusion, thus helping towards doing good for others.

4.9.3 Justice

Justice refers to the researcher's avoiding the exploitation or abuse of participants. The researcher needs to recognise the vulnerability of the participants (Orb et al., 2001). This was relevant in this study with regard to issues sensitive to the participant. There were instances, for example, during an interview with one participant with a disability where he/she shared an experience that had an emotional impact on him/her or another where a participant chose not to elaborate on a certain experience. The researcher respected their decisions not to share their experiences or allowed them space if the experience being discussed resulted in emotional or psychological vulnerability. Participants have the right to fair treatment and privacy (McIlfatrick, Sullivan, & McKenna, 2006). The interview was held in a venue of the participants' choosing to ensure privacy. The participants were all treated in the same way and with respect.

4.9.4 Confidentiality

Ensuring confidentiality is a very important ethical principle and participants should be informed that their details and responses will not be accessed by other parties (Broom, 2006).

From the very beginning of the research process, the participants were ensured that confidentiality would be maintained. Confidentiality was ensured through the use of pseudonyms. When issues were raised by participants that impacted on questions asked to other participants, the researcher ensured that the identity of the participants was not compromised. For example, this occurred when a question related to an issue brought up by a participant with a disability was put to a family member.

All the data collected has been kept in the strictest of confidence. It was kept in a safe place. The University Ethics protocol requires that the data will be kept for 5 years and destroyed once the study is completed. This is the right of the participants (McIlfatrick et al., 2006). This ensured that all the data was managed maintaining confidentiality.

4.9.5 Non- Maleficence

The principle of non-maleficence ensures that there is no exploitation or harm done to the participants. Harm does not only refer to physical harm but the researcher has to ensure that there is no psychological harm as a result of the participants being involved in the research process (McIlfatrick et al., 2006). The researcher was aware that in talking about their experiences, the participants might experience emotional distress, especially participants with disabilities and their families, and she had to be very sensitive in these situations. In instances where this happened, she was empathetic and allowed the participants the space and time to express their emotions. Moreover, she made the participants aware of professional psychological support available should they require it.

Respecting the views and opinions of the participants was crucial throughout the research process.

4.10 CONCLUSION

This chapter describes the research paradigm, design and methods applied in this study. It includes a presentation of the data generation and analysis process implemented. The researcher also discusses some of the challenges experienced during the data generating process. Chapter five presents the findings of the study.

CHAPTER FIVE: FINDINGS

5.1 INTRODUCTION

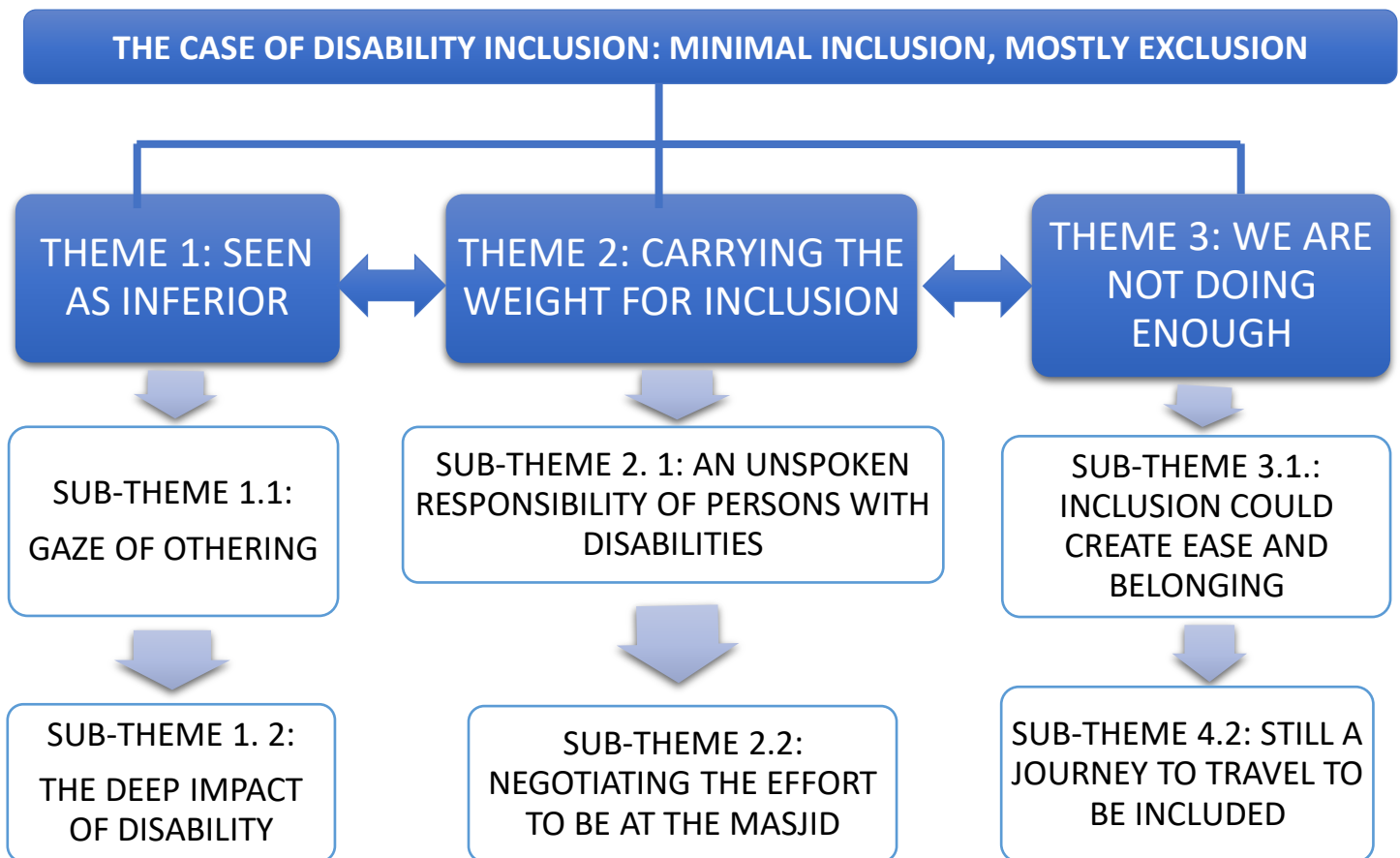
This research set out to provide insights into the research question: “How is disability inclusion interpreted, experienced and enacted by persons within the Muslim Ummah in South Africa?” In this chapter, the findings of the integrated data analyses are presented. The case of disability inclusion in the Muslim Ummah is identified as one of “Minimal inclusion, mostly exclusion” and is constituted by three (3) themes namely: ‘Seen as Inferior’, ‘Carrying the Weight of Inclusion’ and ‘We Are not Doing Enough’. Each of these themes has two (2) sub-themes as illustrated in the figure below:

The concepts of the Capability Approach were key in engaging with the findings. The lens of the Capability Approach allowed the researcher to identify and think through the opportunities for participation within the Ummah. The Capabilities Approach with its focus on building social connections and analysing the extent to which the social, cultural and religious dynamics of the context contribute to expanding or impeding choices available to individuals within a community is useful in identifying the dehumanising and invisibilising of persons with disabilities within the Ummah. Highlighting that choices and freedoms of persons with disabilities are extremely limited (Trani et al., 2009).

More specifically it assisted with identifying the dearth of capabilities or substantives opportunities afforded to the participants within the Ummah in order to achieve functioning (the ‘beings’ and ‘doings’). This is reflected in the naming and contents of the themes and sub-themes.

Figure 5. 1: The Case and Themes

The presentation of the findings begins with a description of each of the themes and sub-themes and concludes with a description of the case.



5.2 THEME 1: “SEEN AS INFERIOR”

A common thread amongst participants was that persons with disabilities were seen as inferior to non-disabled persons within the Muslim Ummah. This view of disability and persons with disability as inferior was apparent in the participants’ views of disability. An expectation of ability was seen as an accepted standard of society. Riyadh’s description of disability emphasises the concept of deficiency, stressing normality as being the ideal.

“Disability to me is not having the hundred percent physical or mental capabilities of what, a normal, the norm is to run, skip, jump, scream, eat, all of those things and with the disability affects all those I think with normal functions of day-to-day activities.”

(Riyadh - Participant with Quadriplegia)

The vocabulary used to describe disability reflects that participants compared persons with disabilities abilities to those of non-disabled persons. Dilshad's explanation of disability also reflects this comparison and highlights the normative ways of being and doing:

“My understanding of disability would be, not being able to do, physically or mentally or intellectually, up to the normal or average standard of normal seeing and I feel, so it will just mean impairment in mental ability, physical ability or intellectual emotional ability.

Yes, it's completely different from the normal it is different. Normal is average, average is.... But physically. Everybody walks, abnormal mean not to walk, because the majority of people can walk so, I am fine it's just different it's not necessarily bad... just again that it does not mean that it is bad or disabled means you know lack complete lack, of anything or worse than anybody else cause we are diff... we are there are sets in life where disabled people flourish better than able bodied people and...”

(Dilshad- Participant with a mobility impairment)

Dilshad reiterates the deficit of the difference by using words such as 'abnormal' to describe how disability moved away from a 'standard' which she considers 'normal'. She describes disability as being measured by not meeting this standard when reflecting that many persons with disabilities and non-disabled persons may take issue with the term 'abnormal' to describe disability, Dilshad expresses her comfort with the term:

“Yes, I am completely ok with it...A lot of people would say if they say umm 'oh but normal, I mean, I mean if they around me and then they say I mean not normal you know but I really don't see a problem with that because it is abnormal to be different but it is not to say that abnormal is bad, I just don't feel why, is it bad to say that something is different. That is just my look on it, but I know abnormal is just not average so that does not mean it's bad.”

(Dilshad- Participant with a disability)

Ayesha, a deaf participant, referred to disability as being a physical impairment impacting on a person's independence but as a Deaf person, she doesn't identify as a person with a disability.

"Disability is such a broad concept and a broad term. Within a South African context though, I would define that I am Deaf, one part I would say that I am not disabled because I have no physical disability, I am very independent I can do whatever physically. One barrier though is that communication barrier and that communication barrier itself is my disability, so, it is a little bit of an ambiguous answer."

(Ayesha, Participant with a disability)

Although Ayesha does not identify as a person with a disability, she sees her communication barriers as disabling her. Similarly, Ismail, a Deaf participant, does not see himself as being a person with a disability. However, he acknowledges that he is treated differently and is seen as inferior by the non-disabled community because he is Deaf.

"He doesn't see himself as someone with a disability but him being Deaf within this community, when people see him all they see is his Deafness and they kind of believe that being Deaf there is something wrong with you and you are not normal. So, they don't see him as an individual, they see him as being Deaf you know."

(Ismail, a participant with a disability, as interpreted by daughter, Tasneem)

Neither Ayesha nor Ismail identifies as being persons with disabilities but they report experiencing disabling barriers. Both Ayesha's and Ismail's interpretation of disability distinguishes between a person who is Deaf from persons with disabilities. This could be attributed to the influence of the Deaf culture on their perspectives. Ayesha draws comparisons between disabilities.

"So, I think when it comes to disability, personally I think that Deafness is the worse one of them all and it's clearly defined, it's visible."

(Ayesha, Participant who is Deaf)

The positioning of some disabilities as more 'severe' aligns with an ableist standard of viewing and comparing the abilities of persons with disabilities. This creates competition for visibility and priority with regard to support for disability inclusion. This may create tension between persons with disabilities as it influences their experience of disability inclusion. Amongst the Ulema, a binary view of ability and inability was also apparent. Referring to persons with disabilities, Imam Saleh uses a normative narrative that places persons with disabilities at a deficit and secondary to non-disabled persons.

"My understanding of disability is a person who is far less privileged than what you are. For example: some may not be able to walk to the Masjid. Some may not be able to hear what is being said. Some might not be able to talk to the next person. Some might not be able to see what is happening around them. Those are the things that I would refer to a person as has a disability and as far as having access to what normal people have."

(Imam Saleh, Ulema)

Similarly, Moulana Mohamed's interpretation of disability positions persons with disabilities as inferior:

"Okay, disability my understanding is it's a person's sometimes imperfection either in their body or either in their understanding and this is natural. A person is born sometimes with an imperfection physically or emotionally, mentally, and where this person now needs help [inaudible] disability to function normally."

I have never looked at a disabled person differently in the sense that condescendingly or in the sense that pitied them on. It is just some people are born Deaf; some people are born Blind."

(Moulana Mohamed, Ulema)

Moulana Mohamed says that he does not see persons with disabilities differently, but his explanation is contradictory. Sarah also focuses on inability, defining the person in terms of their impairment:

“Anyone who has special needs or cannot physically perform what a person...this is normal in inverted commas; they cannot perform physically what a person who’s all their limbs and everything that are functioning. Their whole body is muscles, and everything are working properly they cannot do but that’s the limit of it because they can get around it. There are ways for them to work around it.”

(Sarah, non-disabled person)

Families of persons with disabilities also have their unique interpretations of disability. Family members tended to associate disability with incapacity and illness or as difference. Radiya views disability as incapacity, associating it with illness:

“My understanding of disability, if you are not capable, besides losing one sense, one sense obviously that is a very physical or mental or visual disability and there are times where people do become disabled because of illnesses as well so these various things that can be...that can make people disabled.

“Well, if someone gets a stroke, so they become sort of disabled. So, you are not capable of leading a normal life but there is rehabilitation and with rehabilitation some people do improve. It all just depends on the severity.”

(Radiya, Safira’s sister)

In focusing on inability rather than ability, persons with disabilities are seen as lacking in one way or another, they are seen as inferior.

The language used by participants in their interpretation of disability emphasises the ableist narrative of disability. This narrative of ability, deficit and inferiority, influences how persons with disabilities are viewed within the Ummah and the way inclusive spaces are created for

persons with disabilities within the Ummah. This is elaborated in Sub-theme 1.2 'The Gaze of Othering' and Sub-theme 2, 'The Deep Impact of Disability on the Family'.

5.2.1 SUB-THEME 1.1.: THE GAZE OF OTHERING

Participants with disabilities describe being frequently 'stared' at by non-disabled persons and say that this leads them to feel excluded and othered. This occurs in different situations and spaces, that is, in professional spaces, public spaces and in the Masjid. Dilshad elaborates:

"I always have this running joke with my family, my brothers will push me in the wheelchair while shopping in malls because I use the wheelchair for long distances and things....when we go to like say I go to, this may not sound very well, so say I go to The Waterfall Mall, the people, the stares you get because of the community, because of, they are not educated in that sense because they are not used to seeing someone like, the STARES, the questions and the way the mothers pull them and the ways the mothers react and I mean that's mostly Muslim, The Waterfall Mall is just like the most Muslim mall here in Cape Town, the way they pull them and they just make it such an ugly thing and me and my, I like to approach children, I love teaching even if I see them standing I would like to call them and answer their questions it's an opportunity like especially with children I want to answer them but when a mother just pull them away, it's such an ugly thing and like. They don't know why they are being pulled away and they feel like they should always be afraid when they see someone in a wheelchair or they should like don't look because they don't even know why they not looking because they taught just don't look, look away and just it's, I mean stares."

(Dilshad, participant with a disability)

Dilshad's mother explains how being stared at influenced Dilshad to remain home rather than to use a visible assistive device.

"She wouldn't use a wheel chair she struggled until we said to her, 'Dilshad, we need to go to shopping centres; we need to go out, I need to take you with me. We are going to put you in a wheelchair;' and she wouldn't go in a wheelchair.... She doesn't like to because she says like people stare, children are fascinated with the wheelchair."

(Fazila, Dilshad's mother)

As someone who is Blind, Safira explains how the staring instead of engaging with the person with a disability leads to her feeling excluded. This is something she experiences all the time, in different spaces.

“This GAZE thing happens yoh! EVERY TIME you know if I will walk in today to a meeting right maybe at Radio Mubarak radio meeting right.....But I will tell you an incident real life incident that happened right. I walked into a meeting I was a radio presenter you know right.... And people who know me to, I will walk in and no one will come and talk to me they will all gather around their own thing eventually the chairperson said why they don’t include and I agreed to that so that whole thing about GAZE and that not coming forward to communicate to us is a thing that happens to this very day.”

(Safira, participant with a disability)

Safira did not only experience the looks that left her feeling excluded in a professional setting but she also experiences these stares when out in public spaces. Although Safira is Blind and cannot observe the looks and staring, she still feels them.

“Every day, every time”

Safira felt that non-disabled persons should speak to her to understand more about disability rather than just staring at her.

“It happens to me every day, even to me this day because when I walk around with my children or my friends and they still tell me, people will just STARE at us without even asking any questions, you know and just stare their facial expression and it happens even today and that is one of the things that is still very alarming in our community where people will just gaze and don’t walk up and get information.”

(Safira, participant with a disability)

Persons with disabilities' family members each had experiences of being gazed at too when out with a person with a disability. Dilshad's mother described how Dilshad's brother calls the staring 'Stare Much.' Radiya (Safira's sister) also explains:

"It's only sometimes when we we're going out some people will just look sort of... They will look because they can see the person is not, she doesn't have eyes like you and me she has got different kind of eyes."

(Radiya, Safira's sister)

Tasneem also experienced these looks, felt both by her and her father. She felt protective towards her father, wondering about the looks and assumptions that non-disabled persons held of her and her father.

"As a young child in school, I was never embarrassed of my father however I was always wary as to how my friends would react when they would meet my father. I would sometimes notice them looking at him strangely or frowning upon hearing his voice, as it does not sound the same as an individual that can hear. This often made me feel pity towards my father. And Sometimes when I would go shopping with my father, whilst standing in the queue we would engage in conversation (a mixture of sign language and verbal speech). I would often notice that it was mainly the Muslim individuals who would stare at us, as if they had never encountered a hearing-impaired individual communicating before."

(Ismail, a participant with a disability, as interpreted by daughter, Tasneem)

Safira poses a very pertinent question challenging people who stare at rather than approach persons with disabilities:

'What is it that makes people afraid to come up and approach us? They would rather be comfortable to be gazing or even, you know, just making their assumption so that they won't come.'

(Safira, participant with a disability)

Participants questioned that people felt that it was permissible to stare at the persons with disabilities rather than engaging with them. They expressed that many untrue assumptions appeared to be made about persons with disabilities and this had an influence on the way they experienced disability inclusion. Some participants also described the looks they received from the attendees at the Masjid.

"I've gotten a lot of stares and even like direct comments from mostly old people who don't really or have little or have very little tolerance for accepting of different people because they just believe that mothers and kids should just stay at home, women should stay at home. It's just their belief so I know a lot of people who aren't allowed to even walk with crutches in the Masjids."

(Dilshad, participant with a disability)

Viewpoints of disapproval, communicated directly and through the gaze displayed by the non-disabled persons at the Masjid contribute to the exclusion and a sense of not belonging felt by persons with disabilities. Despite the looks that she receives, Dilshad does not allow these stares to deter her from performing her Islamic obligations.

"I walk no matter what because I know that Allah wouldn't make anything difficult for me and if I have to answer to him why I never went to Masjid, he will be like, that's making difficult for yourself there was no ruling on you just not going because you have walking aids that would be there."

(Dilshad, participant with a disability)

For Dilshad, her attendance at the Masjid, is for the sole purpose of pleasing Allah and she chooses not to allow the stares to impact on her choice to attend the Masjid to pray. She also highlights the point that non-disabled persons do not easily accept difference.

"Of course, of course, like the aunties, like I said again and not just that like the children will also like it's almost like they have never seen someone in their whole entire life and I mean it's beyond me, it's because we people with disabilities are like, believed to, we are taught basically, not taught really but we are kind of taught to just stay at home"

so I mean if I had to stay at home that day that child would never have seen someone in their life up to now."

(Dilshad, participant with a disability)

Riyadh echoes this sentiment and expressed the position that if disability is hidden, then no awareness is created. He thus believes that regardless of the looks that he receives, he has to be participate in public.

"And that's the thing we need, we as impaired need to get out there, let people look at us in any way they want to but that would create the awareness that we are there and that awareness is more important than anything else because that's starts, where it starts."

(Riyadh, participant with a disability)

Ashraf explains that, as a person with a disability, he is expected to sit in a particular area when praying. He explains that he receives looks of disapproval if he veers from this expected norm. He would be seen to be challenging the status quo.

"Look, basically maybe I am judging somebody else and I am being too judgmental, people look at you and say, oh, you with a wheelchair now and you right in front and people know in the Mosque, you have, where old people sit you to have a lot of chairs so why don't you sit there by the old people and that's where you should be sitting you know. There's a look that you get in there to say but, why are you being different, we have created this whole 'Suf 'here for those who must use chairs. That's ' how they look at you and maybe I'm putting myself in a box and I shouldn't but that's how people look at you and I'm thinking that's what they thinking."

(Ashraf, participant with a disability)

In this instance, persons with disabilities are expected to remain on the periphery, not able to freely practise their Deen³ as other non-disabled persons, thus being dismissed and invisibilised.

The Gaze on persons with disability has many intimations, but the power is mostly situated in the hands of the Looker, making the person with a disability feel lesser than, and inferior to, non-disabled persons. Gaining knowledge about disability could help to dispel the myths and stereotypes that many people still hold about persons with disabilities. Ismail shares how he does not have access to Islamic education since there were no facilities for such education for Deaf children when he was growing up. The responsibility for his learning fell to his family and, in particular, his sister since none of the Ulema took the responsibility to teach him.

"He went to girl's Madrasah because he had to go to Madrasah with my aunt because she's the only one who could communicate with him so he would sit in a class full of females because in the boy's class of course they would just stare at him because he doesn't understand, they can't communicate. That's the reaction from the Moulana, you know, that's teaching the girls because he's seeing him in this class and obviously seeing it as, like a disgrace but actually not really understanding that this child can't communicate and the sister is there, helping him, you know."

(Ismail, a participant with a disability, as interpreted by daughter, Tasneem)

This type of reaction from the Moulana demonstrates how the Ulema are not conscious of the needs of persons with disabilities. As a child, being the only male in a female class was a deeply embarrassing experience for him.

Ayesha attributed the sense of inferiority as arising because of Islam in general even though it was the actions of those within the Ummah that contributed to the marginalisation of persons with disabilities.

³ An Arabic word which refers to the way of life Muslims adopt to comply with divine law, encompassing beliefs, character, and deeds.

"It's funny for me that when I social, I love socialising with many different people my white friends, my gay friends, my black friends, I find it very interesting though that non-Muslim, my non-Muslim friends, like I have a braai or party have various ethnicities, they would want to communicate with me; when I go to the Muslim community though they would be very prim and proper, and they would be so apprehensive to communicate with me. In Islam it feels to me as if I am seen as inferior, I don't want to come across as negative but that's my experience."

(Ayesha, participant with a disability)

According to Islam, all individuals are equal, but this was not reflected in persons with disabilities' experiences of the Ummah. Radiya expresses a similar sentiment, feeling this inequality, especially from the Indian community. People staring because Safira's eyes are different to those of 'others', to non-disabled persons.

"Especially our Indian communities and if I am holding Safira and we going they will think that she is not only blind but Deaf and dumb because the others will ask me all the questions and I would be sort of cool about it and answer them but Safira will take it in a very annoying way."

We (Safira's siblings) sort of, we didn't feel bad because we can see they are curious and I think we would have done the same so we wouldn't feel bad but her second son, Zain, he would feel bad about it. He didn't like the idea of people looking at them."

(Radiya, Safira's sister)

Radiya did not take issue with people looking at them but Zain (Safira's son) felt this othering and the exclusion that his mother experienced as well. So, who sets the norm of what is different and what is not?

When the non-disabled person does not engage with or give voice to their curiosity and only stares at the person with disability it contributes to a sense of inferiority that is accompanied by many emotions for the person with a disability. Persons with disabilities are left wondering

about what is going through the minds of non-disabled persons when they see a person with a disability. Assumptions are made on both sides – by the person with a disability and non-disabled persons but there is little opportunity for honest, open conversations about disability in these situations. Instead, persons with disabilities and their families experience a Gaze of Othering. The harmful effect of this gaze and the associated feelings of inferiority was articulated by persons with disabilities and their family members, as elaborated in sub-theme 1.2.

5.2.2 SUB-THEME 1.2. THE DEEP IMPACT OF DISABILITY

The experience of disability and disability inclusion affect persons with disabilities and their families. Family members experience feelings of isolation, exclusion, and a sense of not belonging to the rest of society. This experience is deeply emotional and personal. Noori reflected on what it was like when Imran became disabled, explaining the complexity involved and the myriad of emotions.

“Ya, I mean we sit here, and we talk quick sentences but that is not the reality it is not a little sentence here. It is huge, your whole life changes, your children’s life change, your personal independence changes as well as his independence changes greatly and mine also, your focus, your mind, I think your whole personality, probably the way you think. It has to, for you to survive you have to adapt.”

(Noori, Imran’s wife)

The transition from being non-disabled requires change for the families. Although adapting to this change may appear easy, persons with disabilities and their family describe the complexity that they confronted.

“When you meet Imran or myself you might say, ‘oh, this is a piece of cake,’ because we both have that nature of giving that impression but it is not a piece of cake and it is not a piece of cake for us.”

(Noori, Imran’s wife)

This resonates with Riyadh’s family as well, as Aslam (Riyad’s father) explains:

At 28, Riyadh was in his prime when he became disabled. As soon as the family was informed of the nature of his disability, they realised that many changes needed to be made. The immediate concern was to look at access.

“I had realised that our house and many other things, even our vehicles are not equipped for persons with disabilities, especially with the type of disability that he was coming with. We then and, and I’m sorry about that so immediately I realised that the house is not user-friendly for him, secondly the beds are not because he had to be turned often, thirdly the taps and everything, the whole house.”

“We had to rearrange our lives and stuff, change our lifestyle, change the way we do things, we became closer as a family that’s why these are positive things that immediately he like a care and support structure from siblings, aunties, uncles, grandfather and grandmother.”

(Aslam, Riyadh’s Father)

Although Riyadh’s family was supportive, Aslam also admits to feeling helpless as a parent.

“You can’t show anything to him, you can’t show to anybody, you can go to your room alone and cry and but that is it, you can’t cry because you must show your strength because at the end of the day there comes a time when you must stop crying. You cried when the accident happened, you cried when they told you that he was and now and then you cry on his birthday just to think or when you see him sitting there depressed and stuff as parent you just cry not because you felt sorry for him because you are helpless as a parent, because you the one that supposed, to help him but you are helpless, there is nothing you can do about it, so the crying stops.”

(Aslam, Riyadh’s Father)

Like Aslam, Noori also goes through similar emotional times.

“Ja, and in a blue moon Imran and I will also sometimes, we do sit and cry together but we are lucky as I said we both say do not do that because we are so lucky.”

(Noori, Imran’s wife)

Tasneem explains her father's (Ismail) experience in a social setting and the impact this experience has on him as an individual as well as a father and her as his daughter:

"In terms of a Deaf individual, he feels that he isn't included in the community and he feels that it's not going to happen anytime soon, he says like whereas his kids see that when we go out, like say we go to a social event, he's always alone, he's like isolated, you know, because everyone can communicate but he feels that he's on his own."

Tasneem identifies the difficulty with navigating the isolation:

"Being a family member of an individual with a disability can be an emotional rollercoaster. I remember when I was younger."

(Ismail, a participant with a disability, as interpreted by daughter, Tasneem)

It was distressing for his family to witness this exclusion and isolation but even more so for Ismail who feels it all and knows that his family is also observing what is happening.

Dilshad's family never questions the need to include her and never considers her disability a 'problem'. She is always included in all aspects of family life and if Dilshad is unable to access a certain place, then the family does not go there either.

"So, we make our world according to her. We don't go to the beach because Dilshad doesn't go the beach. We don't go to Ratanga Junction because they won't allow her in there, right. So, we do have a problem with access, we do have a problem with mobility, we do have a problem with inclusivity. We have a problem and therefore our family is incapacitated. So, we will only do things that she can do with us. It disables us also."

(Fazila, Dilshad's mother)

Dilshad's family members took principled decisions about where to go, based on access. They consider whether spaces are accessible before entering public or private spaces, highlighting how disability inclusion is experienced by the collective.

The multi-layered experience of disability and disability inclusion deeply affects participants with disabilities and their families. This is exacerbated by the reference to persons with

disabilities as inferior and the deficit-based vocabularies used to describe persons with disabilities. This reflects a dominant ableist viewpoint that is evident in the gaze that diminishes persons with disabilities and their families. Theme 2 details how persons with disabilities attempt to combat being seen as inferior.

5.3 THEME 2: CARRYING THE WEIGHT FOR INCLUSION

This theme illustrates how persons with disabilities, in many instances, feel responsible for negotiating their inclusion and ensuring that persons with disability are comfortable with regard to their disabilities. Ashraf describes an experience at his local Masjid that left him so humiliated that he did not return to the Masjid for a number of months. His experience demonstrates how the leadership within the Masjid lacked knowledge around disability and disability inclusion and did not make the effort, firstly, to understand disability, and then to use this knowledge to welcome and include all within the Ummah.

"In the beginning one of the mosque that I went to which was the Jumma Masjid one of the Mutwallies came to me and said, your wheels are dirtying our carpet, you need to come with a cover and put it on your wheels and I did not go back to that mosque for months purely, that the man was ignorant to tell me that my wheels are dirtying the mosque and carpet but also it belittles a person and I felt belittled I felt discriminated I felt that...I felt that I am not belonging here although the mosque wasn't fully accessible and things like that you know you making the effort to be there, you making that effort to make that connection with yourself, with your Creator and then a human being comes and tell you, you not in the right."

(Ashraf, participant with a disability)

Instead of ensuring that the space was inclusive of him, Ashraf was made to feel as though he did not belong in a space that he considered sacred.

Ashraf used his agency in finding out the correct Islamic ruling.

"So I went to the Jamiet and spoke to the Ulema there and said this is what's happened to me. I agree with it if my wheels are wet its gonna dirty the carpet or if it's raining

and all that I understand & I'll dry the thing and the Moulana then told me, 'no Ashraf, the dust that you have on your wheels is like performing tayammum⁴, so even if you don't have Wudhu, if your wheels have made three full revolutions it's like you have it's like you have you have wudhu already because of the dust on the ground.' That's what he said to me, 'don't feel bad you stay on these'; this particular Moulana made it easier for me to understand and made me feel comfortable."

(Ashraf, participant with a disability)

The Ulema made no effort to educate themselves and create inclusive spaces for persons with disabilities. Instead, persons with disabilities took responsibility to access necessary information related to disability, leaving non-disabled persons unaccountable. Dilshad was prepared to put her health at risk in order to avoid conflict at the Islamic school she attended.

"So, they made my class stationary but also like it was just so, [laughter] it was very alienating because everyone else is, who doesn't want to walk to their classes, it's such a big thing to do but because of me, we all had to stay so it was just so, when I went back to school, I said no I will walk it's fine because I just really didn't want that again, like taunts. YA, and I mean like of course they don't mind but they do mind. I, like persons with disability, we do sense if you really want to do something. Just a point of making everyone feel better and I mean keeping the class upstairs is also just another example of making everyone feel better I mean. Ya, it's like it's fine, I will walk up every day if it will keep the peace basically, so ya, it's emotional, the emotional thought that goes behind everything is a lot."

(Dilshad, participant with a disability)

Dilshad's experience highlights the lengths that a person with a disability has to go to fit in and make non-disabled persons comfortable. She elaborates further:

"Yes, I, if I walk up the stairs then I will just be out of breath and they will be talking and we will have a conversation, my friends and I and then I will have to like, I have learnt how to talk while trying to die, while I am kind of dying it's like cause, if I like

⁴ Tayammum: The Islamic act of dry ritual purification using a purified sand or stone or mud in place of ritual washing if no clean water is readily available

stop and breathe or something then they will be like “Are you ok? M-must we do anything? Let’s carry you?” ‘I really can do it but I just need a second, but they don’t understand that, so you make them feel comfortable, you make them feel it’s ok at whatever, ‘cos really it’s not, their, it’s not their issue and thing, they really don’t, they wouldn’t know any else, any other better... like ‘cos parents teach you oh help, help, help but sometimes you really just”

(Dilshad, participant with a disability)

Dilshad’s friends were unaware of the emotional and physical impact of her efforts to normalise the situation.

Persons with disabilities carry the weight of the responsibility related to disability. This responsibility includes creating awareness of disability, making others feel comfortable about their disability and finding ways to fit into inaccessible environments. This imbalance of responsibility is implicit, as described in sub-theme 2.1, “The Unspoken Responsibility of Persons with Disability to Create Inclusion”. Persons with disability are particularly affected by the extent to which they are “Negotiating the Effort to be at the Masjid” as demonstrated in Sub-Theme 2.2. below.

5.3.1 SUB-THEME 2.1: THE UNSPOKEN RESPONSIBILITY OF PERSONS WITH DISABILITY TO CREATE INCLUSION

There appears to be an unstated assumption that persons with disabilities have the responsibility to create inclusive spaces for themselves. Since there are inadequate efforts from non-disabled persons to create full inclusion for persons with disabilities, this responsibility falls to the persons with disabilities. Participants with disabilities explain the heavy load of carrying this unspoken responsibility. Ismail explains that he has to be constantly vigilant to check whether anyone is trying to connect with him or get his attention. He repeatedly has to explain to people that he is Deaf and not ignoring them when he does not respond to them.

“Like wherever he goes, say he’s at the gym or at the Masjid or wherever, he needs to be alert all the time to other people trying to get his attention because if they don’t know that he’s Deaf, they get angry and think that he’s ignoring them. So, he feels like he’s apologising all the time for being Deaf. When he meets people and say for example, like he says, “No, I’m Deaf” and they’ll respond, “What?” because they like in an aggressive way, if saying sorry kind of brings them down and makes them think like,” Oh, this person is not being rude or aggressive.”

“He feels like they are more receptive to listening if he apologises....” He said he feels like he constantly needs to be explaining, he says, it’s like exposing himself wherever he goes, like my identity is, “I’m Deaf” you know, it’s the first thing that he’s saying to people. So, I think he’s also just saying that he’s scared if people think he’s ignoring them, that they going to fight with him or become aggressive but actually he just didn’t hear them. So, he’s just saying like he’s reiterating that twenty-four hours a day, he just feels that he needs to have that increased sense of alertness. ”

(Ismail, a participant with a disability, as interpreted (in the third person) by daughter, Tasneem)

Persons with disabilities make non-disabled persons feel comfortable by using humour, staying silent or apologising. Safira’s frustration led her to resort to silence in order to avoid further conflict, even when it impacted on her right to pray.

“ I am just saying to this day you have to keep, to showing people and sometimes you do get fed up you, you reach a point and say, ‘ hey, what the hell?’ kind of thing.”

(Safira, participant with a disability)

Riyad highlights the amount of emotional effort that he invests in trying to be included in the Ummah, revealing that the toll of the battle leaves him considering retreating.

“For people with impairments it’s such a major effort, um, emotional effort to want to actually have things in a way that allows you to be part of everything that you come

to a stage, where you just give up because the fight is sometimes so huge and the wall to jump over is so big that you realise you know what, why do I need to put myself through all that effort and stress where I could just, you know stay in my space and do it the way I'm used to or do it in the way, it works for me, this, this is a very dangerous place, it's a very dangerous place because (pause) it's a very dangerous place because what it does is it basically it ,it, puts the aspect of disability highly and firmly, at basically (at the door of the person with a disability), just allows it to happen without, without (non-disabled) coming up with better ways to have people with differences included."

(Riyadh, participant with a disability)

Riyad acknowledges that if the person with a disability is not determined to be visible and take on the responsibility to be included, non-disabled persons will not make the effort to create inclusion. Ashraf expresses a similar sentiment, drawing attention to the tension between putting in the effort to be visible and using his agency to take on the responsibility of creating inclusion for himself or avoiding conflict and not bringing attention to himself. Ashraf speaks of an incident in the prayer place at a Mall where a lack of understanding of his situation led to insensitivity and embarrassment:

"Typical example, the Jamaat Khanna at one of the Malls and when you there you... the Jamaat Khanna is breaking up into two sections, the upstairs section, which is quite big and you got the downstairs section so.... one of the Musallies and a good friend of mine gave the Adhaan and people said lets go and read and he said we will leave about three or four Musallies, whoever wants to read downstairs so that Ashraf can read in Jamaat, so he said, so that the brother in the wheelchair can read in Jamaat, the others that want to go upstairs let's go upstairs and perform Jamaat. So I go and sit right in front and here comes a youngster, 'Come brothers, we all need to go upstairs why must we be making two Jamaats,' another East African brother as well which was with this guy said, 'We're doing this because of the brother in the wheelchair....', and the youngster that said, 'Let's all go up. I know him. I looked at the guy and I, "Is this the way we are brought up? Is this our Islam?'

"I don't raise my voice, or I don't make these announcements in the mosque or in the Jamaat Khanna because you, you, I just want like to carry on, but sometimes you have to take the chance and say, take the lead and say, 'But brothers, we doing it because it's me.'"

"So, I just keep quiet and then people are talking for you so where if you are a true advocate or a true person that is leading, then you should raise your voice or you just overlook things like this."

(Ashraf, participant with a disability)

Even while feeling disillusioned and not wanting to being the centre of attention because of his disability, Ashraf still feels that it is his responsibility to promote inclusion within these spaces and questions through his own agency.

Imran, on the other hand is quite clear that it is his responsibility of making people feel comfortable about his disability.

Imran explains that it is important to 'set the scene' and make people feel comfortable about disability, describing it as 'Making the disability joke':

"You know the trick with disability and the trick with life is step on top of them before they get on top of and you got to actually put the foot forward first without any aggression but make the disability joke. I mean it's like standard joke. Whenever I go to a meeting or if it's someone else's meeting and there is a chairman there, I always come in there and say, 'Ok, whoever thinks he is the Chairman, out, I am the Chairman' and straight away everyone is at ease that I can joke about the wheelchair."

"You need to, because like you know the guy sitting on the other side and I was on the other side. The guy sitting on the other is so uncomfortable, it's like sitting there, like someone who has cancer, and you don't know how to actually address the situation but the guy with cancer can address the situation because he is living it."

"It's my job.

"So, the first thing you have to do is make somebody comfortable. As soon as you make them comfortable and you don't need to lie to them to make them comfortable, you genuinely make them comfortable. You make comfortable and then you just have a jol."

(Imran, participant with a disability)

Even before he engages with the group of non-disabled persons, Imran assumes that he has to make them comfortable and chooses to use humour to do so. He feels responsible for creating this comfort as he remembers not knowing about disability before acquiring a disability himself. However, in assuming the responsibility for dealing with this discomfort, he allows non-disabled persons to abdicate their responsibility to engage with and challenge their thinking around disability. This curtails inclusion from being fully realised since non-disabled persons do not acknowledge that they are complicit in excluding persons with disabilities and that they should be more responsible for disability inclusion.

This unspoken responsibility of creating inclusion borne by persons with disabilities is evident in many different spaces. This is especially brought into focus when persons with disabilities have to negotiate their way to feel included in the Masjid, as discussed in the sub-theme "Negotiating the Effort to be at the Masjid."

5.3.2 SUB-THEME 2.2: NEGOTIATING THE EFFORT TO BE AT THE MASJID

The Masjid is an integral place in the lives of all Muslims, including those with disabilities. Performing the five daily prayers is a pillar of Islam and often involves prayer as part of a collective and is often performed in the Masjid. Participants with disabilities describe the great physical and emotional efforts that they exert so that they can participate in the Masjid. They feel compelled to do this in order to fulfil their obligations as Muslims.

The immense planning needed disturbs what should be a simple act of attending the Masjid to connect spiritually. Riyadh describes how getting to the Masjid used to be a social

experience for him, a chance to connect with his community outside the Masjid as well as within the Masjid. However, this changed for him.

“Let me explain this to you hey, before my accident I use to walk every Friday from my house to the mosque you get the same people they see me, they know who I am you, I mean you become, people get to see you, you get to sit in the same place, you get to sit in the same place, they get to know you and you feel part of everything. I can’t leave my house now in my wheelchair or to get to the mosque because there are pavements in the way, there are speed bumps in the way, there is sand in the way, there’s and that’s (the) biggest issue, the issue is that I am part of a community but since my accident I can’t do what I used to do and that then cuts off the social aspect, it cuts off the way I used to live, hum. Is it something I would like to do yes, I would love to do it, to be able to push myself to mosque and see the same people I saw all those times and talk about everything we spoke about but hum currently there are no aspects in place that allows me to practice that same life I knew.”

(Riyad, participant with a disability)

The inaccessible physical environment around the Masjid limits Riyad’s ability to participate and leads to his feeling that he has lost his sense of belonging within the community. Ashraf describes a similar experience, where going to the Masjid is not a simple decision for him any longer. He explains why he cannot just get into his car, pray and leave.

“Then one of the challenges that I used to face is that on a Friday going to Mosque. The first thing a disabled person, a disabled Muslim man, your first encounter is when you get to mosque from the parking there was no proper accessible parking, getting into it was a struggle, so your mind set is now that whoever is taking you got to find the most easiest parking space, then you have to navigate to find the most easiest way to get in, sometimes it’s not so easy, so you get people helping you....the mere fact that you coming to pray but your mind is thinking how I get out of this place, how did I get in and how am I going to get out so, so, so that’s the challenge.”

(Ashraf, participant with a disability)

Dilshad summarises the effort involved in going to the Masjid, emphasising the planning and preparation required by the person with a disability.

“So, I mean there is a lot of thought that goes into prepare, to work your way around all of these barriers, there is a lot of thought that has to go into it.”

(Dilshad, participant with a disability)

Once inside the Masjid, things do not get any easier, Ashraf describes how his freedom of movement is curtailed as he is restricted to the perimeter of the Masjid.

“You look forward to now it’s time to go for prayer and time to be with the community and things like that but you get there and people like look at you and look down at you and you get into mosque, they will wheel you to one side and that’s where you sit till the Namaaz is over and till it’s time to get out and it was also for me that being in a place of sacred and you being there with others and things like that but the openness or the awareness or, the all of that hasn’t been, that’s a challenge up ‘til today, it is a challenge in the mosque or Madrasah.”

(Ashraf, participant with a disability)

Dilshad echoes facing similar barriers and challenges since the section for ladies in most Masjids is upstairs. For her, negotiating the stairs is a scary and a very difficult experience. Dilshad brings to the fore the way gender and disability intersect, emphasising that she is left feeling unwanted within the Masjid and, as such, within the Ummah.

“I don’t understand why women go upstairs. I really can’t understand that. It’s, like any barrier, any barrier in any context is almost like I equated to it may sound dramatic but it’s like in apartheid, when they actually say, ‘no blacks allowed’, you actually feel that you not allowed, so to see a step and you are not able, it’s almost like a sign saying like ‘you are not allowed here,’ to me that is what it feels like.”

(Dilshad, participant with a disability)

Dilshad continues to explain her experience of negotiating the stairs with her crutches as a deeply emotional experience for her.

“Like I would also think I would have to arrive early, leave as early as possible because the traffic on the stairs, I mean if you keep up the line I just feel it a personal matter, my Mum always says, just leave them, they have to deal with it, it’s fine, do your thing, take your time but I am not that type of person, I can feel them breathing on my neck, I can feel I am keeping up the line, I can feel I am going to fall if they stampede, if they run down and so it’s just a lot of thought, you have to leave early. It’s just like if you want to go, then much effort that goes into someone with a disability just attempting a Masjid, sitting in Jummah attending Maghrib, so much effort.”

(Dilshad, participant with a disability)

Dilshad avoids other Musallies’ impatient behaviour by leaving the Masjid early, compromising her needs and her time in the Masjid. She has many different thoughts and fears related to keeping safe and not inconveniencing others around her when negotiating her way to pray. Although Islam expects consideration of others, this is not evident in the behaviour of many who attend the Masjid. Ashraf also experiences this impatience of the Musallies after the prayers, with little consideration given to someone using a wheelchair. Having just finished their prayers, it is expected that these Musallies should be more cognisant and accommodating of their fellow Musallies.

“The mere fact that once you finish your prayer and whatever, you now getting out of the mosque and so have this double door that’s in front of you, my son normally pushes me, is that the Musallies are finished and they all just want to get out, so the mere fact of allowing you as a wheelchair user the space is not there, people are cutting across, you fighting their way to the door, you get one or two that would say sorry, this guy in the wheelchair is here, he needs to move out and open the door, but it should have been something natural, it’s like meeting a person, let’s make space.”

(Ashraf, participant with a disability)

Ashraf does not feel any sense of freedom or belonging at the Masjid, instead he, like other persons with disabilities, feels that his responsible to do the work to belong.

“You want to be free you want to be like everyone else, you walk in you do your thing you pray you can do chat and things like that and you get out. With us we got to like think twice, we got to navigate yourself, it’s about mind mapping when you get, when you get into the mosque. You have to look at what is left, right, where do you get out, where do you get in which way will be easier to navigate yourself out of there? Ya, so mentally when you get in there you go to suss the place out, so you got to look around and check around and things like that and that’s always, that happens.”

(Ashraf, participant with a disability)

Ayesha narrated that her father who is Deaf had been attending the Masjid most of his life and is known in the community and yet no attempt has been made, after all these years, to ensure that he could follow the communication. Such attempts would have fostered his inclusion in the Masjid and within the Ummah.

“Yes, he (father) goes to Mosque five times. I asked him if he understands he says no I am just having a moment with Allah that’s all.”

(Ayesha, participant with disability)

The place of prayer, as one of peace and ease, is compromised as a result of the barriers, which means that persons with disabilities do not feel included in opportunities to practise their Deen. A particular barrier that people with mobility impairments experience is the positioning of the shoes at the entrance to the Masjid. It is etiquette for everyone to remove their shoes before stepping onto the prayer mat in the Masjid and shoe racks are provided for the Musallies to store their shoes. However, these are under-utilised and people often rush to pray, carelessly leaving their shoes all over the place. Riyadh describes his experience with the shoes when he returned to the Masjid after his accident.

“It’s taken for granted that people, whenever you come into the mosque you take your shoes off leave it outside and go in. You see it’s not something that people have thought of beyond that moment because it hasn’t, it was never of simply put your shoes in the rack or put it neatly aside and why do we do that and only once I’ve really gone to mosque on my wheelchair and I realized what a bloody mission it is if those shoes are laying by the door or by the railing that I need to push myself up onto so I can go and make Salaah. People don’t understand that. And it’s just short sightedness it’s naivety, ignorance.”

(Riyadh, participant with a disability)

Ashraf had a similar experience.

“The mosque that I go to there is a lot of shoe racks but with the overflow you still have the shoes in the way so you know by the time I come out quite a bit of them are gone but the shoes are still there. The first thing is in terms of awareness and advocacy of people with disabilities is zero at this particular mosque and lots of other Masjids. “

(Ashraf, participant with a disability)

Ashraf captured the depth of this problem in the following photographs:



Figure 5. 2: Image 1: *Depicts the shoes scattered at the entrance of the Masjid which restricts access for persons with disabilities*

“If you look at the photo, if you are at the Jummah prayer which is basically the main prayer on the Friday everyone congregates at the mosque. People are not aware of where they put their shoes or people’s needs. So, whether a disabled person or an old person. So, people just come and throw their shoes on the side and get on to the Musallah and move on. The other thing is that there is a few stools that is put on a pathway at this particular mosque. So even if you have to jump the curb to get on there it is going to be difficult.”

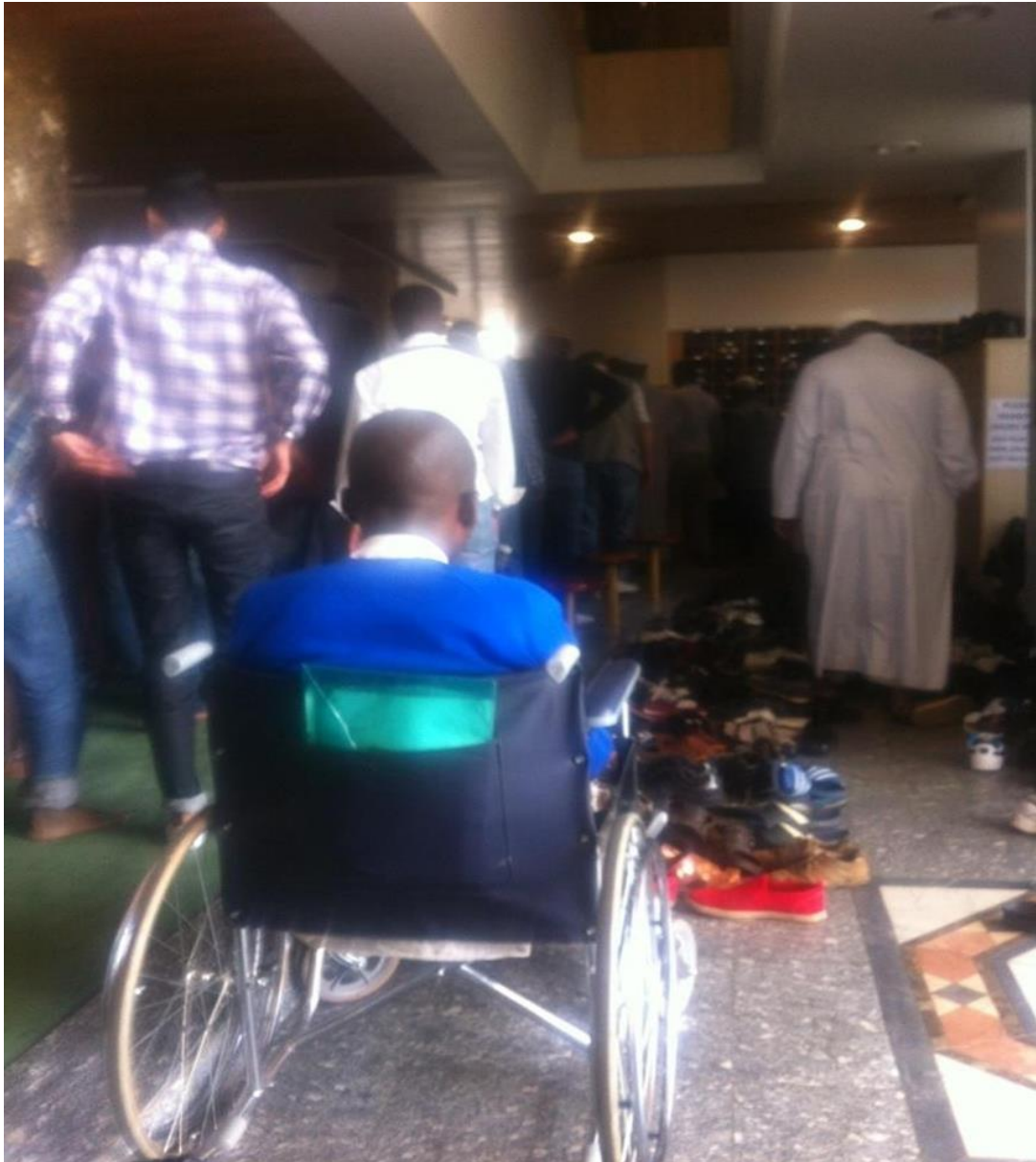


Figure 5. 3: Image 2: Depicts the lack of access for the person using a wheelchair as a result of the shoes scattered at the entrance of the Masjid

This one with the wheelchair and you could see that people moved shoes away so that this guy could park his wheelchair right behind. I am behind him so there are shoes in front of me and behind me. So, we had to move shoes. I don't know who was with me I can't remember on this particular, I can't remember but they had to remove the shoes so that I could be parked in the middle there but I am saying why do we as people with disabilities have to read in the passage? Which you then see all the shoes in the passages."

(Ashraf, participant with a disability)

Dilshad also reflected on this challenge:

“So I mean there is a lot of thought that goes into prepare, to work your way around all of these barriers, there is a lot of thought that has to go into it and I mean it’s shoes everywhere and shelving and I mean a lot of times I wouldn’t get place in for my shoes then I would have to ask someone can you put it on top and take it down and that are all by door, that is so uncomfortable to walk around it’s really dangerous, that is why I like sometimes, people watch you and you can’t like move it out because then they like ‘ hey what you’ then you feel like you doing something wrong like because you trying to push it away and it’s, and also it’s just like leaving early.”

(Dilshad, participant with disability)

Dilshad stresses how she has to very carefully manoeuvre around the shoes so that she does not trip over them. This is an added anxiety for her. Imran sees the shoes in a different light, viewing them as a means of interacting with non-disabled persons when they are asked to move the shoes out of the way.

“Shoes are everywhere thrown around and it’s, basically it has an impact on everybody, everybody keeps their shoes all over but it’s a reality, it really is a reality, and to get past those shoes is, it has not (been) an issue for me because they are light weight things you can just drive over it or wheel your way through, people are very cooperative in that as soon as they see you coming they would move those shoes for you. So, in some ways the positive side of the shoes being there you suddenly, you, you start inter, you start inter, inter interacting with people and they realise that ‘hey this guy needs help’ so they actually participating in your disability.”

(Imran, participant with a disability)

Imran nonetheless concedes that the shoes create a challenge, but he was prepared to do the work, acknowledging that the non-disabled persons do not do what persons with disability expect of them. Riyadh holds the Muslim leadership responsible for not creating awareness around how the shoes affect persons with disabilities. The question arose as to whether the Ulema in leadership are even aware of the shoes as a barrier to freedom of movement.

“Look, I mean, if, you know if everyone is leaving their shoes there, you going to come leave your shoes and go make Salaah, take your shoes and go again. It’s not going to be an issue to you but if the spiritual leader, the Imam, the Sheik, the person standing in front actually makes it an issue then it can actually be an issue.”

(Riyadh, participant with a disability)

An article published in an Islamic publication, “The Majlis”, does not include any concern about the barrier these shoes create for persons with disabilities.

SHOES CLUTTERING MUSJID ENTRANCES

Q. Many people coming to the Musjid have the bad habit of leaving their shoes scattered at the entrance although shoe racks are provided. This inconveniences other musallis who have to sometimes tramp on the shoes when entering. Please comment.

A. Whilst this bad and Makrooh habit may appear insignificant, it in reality displays the anarchy within the hearts of Muslims. They have no care for others. It is haraam to unnecessarily cause inconvenience to others. Kicking off their shoes and scattering it at the entrance, reveal that they were not taught Islamic morals at home by their parents. Thus, they are just too lazy and inconsiderate of others. It is NOT permissible to kick off one’s shoes at the entrance of the Musjid, especially when shoe racks are available. If the careless person who kicks off his shoes at the entrance is wearing expensive shoes, he will not act so carelessly and callously. He will place his shoes in the racks. The love of money constrains him to show consideration to his shoes. The shoes which are kicked off are cheap ones, cheap sandals, tongs and the like which no one will steal.

They also show scant or no appreciation for the ni'mat of shoes provided by Allah Ta'ala.

No matter how cheap the item may be, it is a ni'mat provided by Allah Ta'ala and has to be appreciated and treated with respect. These people have the same evil habit of scattering their clothes at home thereby pleasing shaitaan. Shaitaan loves dirty and lazy people. They are his fertile ground for his wasaawis and snares. A Muslim is required to be alert, tidy and clean at all times. Rasulullah (Sallallahu alayhi wasallam) said: *“Verily, Allah is clean and He loves cleanliness. Therefore, keep clean (even) that section outside your home (despite it not being your property).”*

Figure 5. 4: Article: *The article talks about shoes that are left scattered at the entrance of the Masjid and the inconvenience caused to the attendees of the Masjid.*

Moulana Rashid reflected honestly about the exclusion and discrimination that occurs at the Masjid.

“A Masjid is very important but unfortunate(ly), you would find certain places, I have seen people will greet the people, will make Salaam with them, will incorporate them but certain times we just tend to shun them, Allah forgive us.”

(Moulana Rashid, Ulema)

Echoing Moulana Rashid’s sentiments, Dilshad succinctly sums up the implicit exclusion that persons with disabilities feel when there is not full inclusion within the Masjid:

“It’s like you get that sign like you not allowed.”

Participants with disabilities carry the weight of creating inclusion for themselves within the Ummah. This was demonstrated through the unspoken responsibility for negotiating their way to be part of the Masjid. Persons with disabilities expressed the feeling that they were not afforded the same status as non-disabled persons within the Masjid, feeling that they did not belong and that they were not seen as part of the Ummah. The situations of exclusion experienced reveal the need for greater inclusion to be promoted, as described in Theme 3, “We Are Not Doing Enough”.

5.4. THEME 3: WE ARE NOT DOING ENOUGH

Theme three foregrounds the pressing need for much more to be done to create full inclusion for persons with disabilities within the Ummah, highlighting the particular responsibility for non-disabled persons to do more.

Muslim children, from an early age, are expected to attend Islamic classes, known as Madrasah. This form of Islamic education should be accessible to all Muslim children. However, children with disabilities do not have the same ease of access to it as non-disabled children. Growing up, Ismail was not included in the mainstream Madrasah and this persisted in his adulthood. Ismail acquired his Deafness very early in life and, although accessing secular education was a challenge for him, accessing Islamic education was even more difficult. Ismail was left to navigate around the absence of male Moulanas to teach him. The Ulema made no effort to change this and Ismail and his family were left to their own devices to work out how they would teach him and he could learn the Deen as part of fulfilling his obligations as a Muslim.

“You want to understand the religion, he says he couldn’t because no one here was like, no man in the community was taking the time to explain the importance of certain things to him

“In terms of like Islamic education, when he was younger he obviously went to a Catholic school and he says my grandfather was very strict with him so he had to go for his five times Salaah would always go with him but he said he would go to the Masjid, he couldn’t hear what they were praying and he didn’t know how to pray so

he would just, obviously he grew up learning the actions to do that, then he said when he got a bit older than his sister taught him to read Quran and taught him, that's how he learnt.

(Ismail, a participant with a disability, as interpreted by daughter, Tasneem)

The separation between the Hearing and Deaf people was reflected in the way that the Deaf individuals were not included in the arrangements of Islamic programmes, instead a separate programme was arranged for Deaf individuals.

"He says like he feels like there's like a separation between the Muslim people who can hear and the Muslim people who can't hear, I remember that he's saying that he, so you know on Friday night, they have the Markas so they used to have the Deaf group of individuals who would meet and I think there was like one Moulana who would come and then he would tell my dad, and my dad would tell the other people because my dad could understand but he says he feels like you know there's no, it's not like the hearing people and the Deaf people in the community can have one [inaudible]you know, they can have one talk, it has to be separate."

(Ismail, a participant with a disability, as interpreted by daughter, Tasneem)

The separation within the Ummah did not facilitate any sense of belonging and full inclusion for Deaf Muslims. Mufti Bilal acknowledges that although there is not full inclusion of persons with disabilities, it was not a deliberate attempt at exclusion. He suggests that it could be attributed to a lack of knowledge of disability.

"Principally, I do not think they are excluded and if they are excluded it is definitely not deliberate. Just that maybe the facility has not been created or it has not been thought out. But is it not like they are excluded in a sense based on some kind of prejudice or bias or some kind of disregard for them? In fact, if anything their disability engenders sympathy and empathy for them. So, they are not excluded on the basis of their disability on a deliberate basis, but I think it is more just by oversight."

(Mufti Bilal, Ulema)

Although unintentional, this frequent ‘oversight’ appears to disregard persons with disabilities’ needs. Sheik Luqman concurred that the inclusion of persons with disabilities is not what it should be.

“A simple answer, maybe a diplomatic one would be not as much as they should. They are included but not as much as they should be, but the reality is this, we are only really considerate of disabled when we are affected by it personally.”

(Sheik Luqman, Ulema)

He highlights the reliance on personal experience in rendering disability visible and acted upon. This may defer responsibility to others to provide support, leaving many absolved of this responsibility. Moulana Rashid recognises that the Ulema do not go out of their way and do not do enough to include persons with disabilities:

“No, I think they are not included. I think we have taken life for granted and we have become very complacent. I am okay nothing has affected me so...”

(Moulana Rashid, Ulema)

The Ulema acknowledge that they are not doing enough to address the exclusion experienced by persons with disabilities within the Ummah. While this exclusion is not intentional, it affects persons with disabilities. Sub-theme 3.1. “Inclusion could Create ease and Belonging” and Sub-theme 3.2. “Still a Journey to Travel to be Included” below illustrate how the understanding of inclusion influences the slow pace of creating full inclusion for persons with disabilities within the Ummah, showing that what is being done is not enough.

5.4.1. SUB-THEME 3.1.: INCLUSION COULD CREATE EASE AND BELONGING

Most participants concur that disability inclusion creates ease and belonging, enabling persons with disabilities to participate in all spheres of society. However, there is a of lack of clarity on what disability inclusion actually means and how it should be enacted. Participants’ diverse interpretations of disability appear to contribute to their views of disability inclusion and how this could be facilitated (described in

5.2 THEME 1: "SEEN AS INFERIOR" and 5.3 THEME 2: CARRYING THE WEIGHT FOR INCLUSION).

Radiya views disability inclusion, as manifesting when the person with a disability has access to all places and spaces in the same way as any non-disabled persons:

"Well, that means they are part and parcel of everything that you do. If someone is disabled, you don't just put them aside. They are always there with you, not the forefront or not at the back but they are always with you."

(Radiya, Safira's sister, participant who is Blind)

In addition, Imran, as a wheelchair user, is uncompromising in his view that accessibility, as a right in all aspects of life, is core to disability inclusion.

"I would rephrase it to accessibility inclusion which you can call disability inclusion it's not being able to have access into places where you can interact with and places which according to our constitution our constitutional rights, that have access into everything. So I'm not, not we should have equal access not unequal access we shouldn't kind of or not, we, society itself including my parents shouldn't be pushed into one box now it's easy to say that's a disabled, when at the stadium, said that's a disabled box ah, and what, so I'm talking about inclusion, inclusive schools, inclusive everything because it's not, it's not. Disability inclusion, its disability inclusion or accessibility inclusion is something that's a norm to me, it's a norm, a non-accessible place is an abnorm.... So, it's not a favour we are asking anyone."

(Imran- participant with a disability)

Ashraf proposes a continuum of possibilities for creating and attaining the inclusion that Imran and Radiya refer to. These possibilities range from providing physical access to inclusion within social groups to the empowerment of persons with disabilities.

"Look, inclusion is like on different sphere of how do you take thing you know disability and inclusion is not just having a ramp that's accessible and things like that it's about inclusion in a society and inclusion in a family, it's inclusion in physical so its inclusion in empowerment, have we got the needs to include people so disability & inclusion is

are you allowing the equal access to, take, to take away the burden for the person to be as normal as they are and, that's how I look at things although we have the lovely legislation and policies that's starts from the ground that's from the ocean to the moon, nobody practises it or it's not domesticated."

(Ashraf, participant with a disability)

Like Ashraf, Tasneem believes that society should demonstrate being inclusive by removing any barriers that restrict this full inclusion. She advocates that policies to remove these barriers would create ease and belonging.

"Disability inclusion refers to practices and policies designed to include individuals with disabilities into everyday activities. These policies and practices should aim to identify and remove barriers which hamper the ability of these individuals to participate fully within society."

(Ismail, a participant with a disability, as interpreted by daughter, Tasneem)

Interestingly, Mufti Bilal also emphasises inclusion as being all encompassing and asserts that in keeping with Islamic principles equality of all should be promoted within the Ummah.

"Ja, I very strongly advocate and support for having facilities for disabled people in every Masjid and Islamic organisation or institution, educational institution like Madrassa's and you know organisations that offer welfare, social services, Masjid prayer facilities are available. In other words, the entire spectrum of facilities that are offered by Islamic organisations should have facility for disabled people. It is very important to accommodate for them because increasingly we find people with these disabilities and if they are not catered for, it disadvantages them seriously which is obviously against the very spirit of Islamic teaching."

(Mufti Bilal- Ulema)

Mufti Bilal advocates that anything that does not include persons with disabilities goes contrary to Islamic principles. Fazila emphasises that realising disability inclusion requires giving consideration to one's disability and recognising its accommodation needs.

“My understanding about disability inclusion would be just about recognising that your disability has to be considered. So, somebody has to consider the fact that there may be a disabled person using whatever it may be.....”

(Fazila, Dilshad’s mother)

Family members, Ulema and persons with disabilities support a similar systemic approach to disability inclusion, believing that this would mitigate against persons with disabilities having to do all the work to feel a sense of belonging within the Ummah.

Aslam explains that disability inclusion means ensuring that persons with disabilities can participate together with non-disabled persons. He asserts that such participation is possible when environments and situations accommodate for the needs of persons with disabilities.

“Inclusion is getting, I take from my school set up, is putting people with disabilities in able bodied situations and let them be part, as if there is nothing wrong with them, there’s nothing different with them, it’s just that the environment must be conducive for them where they can, can, can be in that environment as abled bodied person would be but not feel restricted or be further disabled. That is inclusion.”

(Aslam, Riyadh’s father)

This perspective emphasises a shift from a deficit view of persons with disabilities. Hassan explains that the aim of disability inclusion is to create ease for persons with disabilities and that access to the necessary assistive devices helps to create equity for persons with disabilities.

“For me it’s like always to make this life better for them, for people just [inaudible] them also they are normal human beings, they are like us. Or they just need - sometimes they need some extra tools. They need some - maybe I’ll just say some devices. Ja (with) assistive devices we are totally equal normally.”

(Hassan. Ulema)

Disability Inclusion is seen to occur in situations and environments where persons with disabilities experience a sense of freedom and belonging. Noori attests to the influence inclusive spaces have in creating a sense of ease for them as a couple.

“Obviously the more inclusive an environment is, the easier it is for us to cope.”

(Noori, Imran’s wife)

While some participants emphasise a systemic perspective to disability inclusion, some patronising views of the way inclusion should be enacted for persons with disabilities were identified. Yasin’s understanding of disability inclusion reflects this patronising view:

“I imagine...not treat them as disabled or rather treat them like any other person that’s what I would...but I would imagine that to develop people that are disabled so they don’t feel that they are disabled.”

(Yasin, non-disabled participant)

Dilshad brings to the fore the way inclusion could create ease when meeting the needs of a person with a disability but she appears to approach this from a deficit perspective of difference.

“Disability inclusion is just catering to, ‘cos disabled people will have different needs that’s why they call it special needs kids or special needs people, it’s because they have different needs because they have different abilities or lack of abilities that others have so to include them would be just catering to their special needs, catering to their, say an Autistic child, inclusion in schools of their type of play, they don’t play the same as other people do so inclusion would be to play according to their level of play you know, include their understanding include their needs. Just catering to their special needs.”

(Dilshad, participant with a disability)

Moulana Mohamed’s understanding of disability inclusion reflects a contradiction between empowerment and a patronising perspective.

“Inclusion, I would say it means incorporation, love, affection, assistance, help to bring them to...let them achieve a dream and show them motivation and show them that basically there is something that you can...there is a result that you can achieve and this is very important because many of them, because of the disability, they are just living lives as dormant objects, there is no hope and to give them that whole encouragement to say that there is something you can achieve there is a dream that you can achieve that’s what it is.”

(Moulana Mohamed, Ulema)

Similarly, although Fazila raises an important point around education leading to inclusion, her thinking around persons with disabilities also comes across as patronising.

“So, you have to have an understanding and also that people be educated about it because I think people know little and therefore, they don’t want to go there because they don’t understand. So, people have to be informed or educated about people with disabilities and what their needs are. So, for me I just think that we need to accept and make them feel accepted. We have got to reach out to them to tell them that they are also going to be considered.”

(Fazila, Dilshad’s mother)

Fazila, Moulana Mohamed and Yasin, in their interpretation of disability inclusion, see a division between persons with disabilities and non-disabled persons, with non-disabled persons ‘helping’ persons with disabilities to feel included and accepted within society. This reinforces ableist views and reveals the need for education and awareness about disability and disability inclusion. This divide between persons with disabilities and non-disabled persons is also evident when Ayesha advocates for increasing education about disability and disability inclusion.

“Disability Inclusion is very important to South Africa. There are many disabled people that are actually marginalised they are pushed to the side, physically disabled people

in a wheelchair, Blind people, Deaf people or whatever they struggle and when they explain their struggles to me, I realise that there's some similarity, hearing people on the other side don't really understand disability or non-disabled people do not understand the dynamics within the disability community, the various needs, one person would need an assistant, I would need, a Sign Language Interpreter. In some situations, I would need access to making a call another situation I would need access to the airport and to the announcements made."

(Ayesha, participant with a disability)

While participants hold the belief that disability inclusion is important and should create ease for persons with disabilities, their views of the way it should be effected are varied. This might be because a normative, ableist discourse (described in 5.2 THEME 1: "SEEN AS INFERIOR" and 5.3 THEME 2: CARRYING THE WEIGHT FOR INCLUSION) influences how disability inclusion is seen. The separation between persons with disabilities on the one hand and non-disabled persons people on the other, leaves most non-disabled persons with poor understandings of disability. This limits the way that disability inclusion is facilitated within the Ummah.

The implication of this divergent way of thinking is that there is not a unified voice on what the need is and how marginalisation of persons with disabilities is entrenched when disability inclusion fails to happen.

5.4.2 SUB-THEME 3.2: 'STILL A JOURNEY TO TRAVEL TO BE INCLUDED'

Sub-theme 2.1 (An Unspoken Responsibility of Persons with Disabilities) describes how the responsibility for creating full inclusion tends to fall to persons with disabilities rather than being shared between persons with disabilities and non- disabled persons within the Ummah. This sub- theme incorporates the notion that although some aspects of inclusion occur within the Muslim Ummah, the pace of change is too slow and the amount of change is inadequate.

The Ulema acknowledges that while there has been some progress in the inclusion of persons with disabilities within the Ummah, it is not enough; much more needs to be done. Imam Saleh explains that it requires equity in meeting needs within the Ummah.

" People with the disabilities they are part of our Ummah. And whatever privileges we enjoy they must enjoy it on the same level but in a particular different way that accommodates them."

(Imam Saleh, Ulema)

Hassan expresses similar views and highlights how non-disabled persons could do more.

"To me to be disabled or not is no matter at all but the thing is, we human beings we make it difficult for people, the way we build the Mosque, the way we build our houses. Whatever it is we make it difficult. For now, its minimum actually I don't think it's enough because - but that's why I was saying we should not limit it with wheelchair only, it must be - even Islamic publications."

(Hassan, Ulema)

Hassan recognises that information, and not only physical spaces, should be accessible. Riyadh asserts that the Ulema should create spaces to increase the number of persons with disabilities who can participate.

"The people in power, they have the power to change, to say, 'But listen, we only have one person out of ten thousand that comes in a wheelchair, why should we cater for them?' That excuse is bad because that number could grow over night and then you do not want to be the reason why someone does not want to come to mosque. Think about that, that's even bigger than someone making Salaah at the home."

(Riyadh, participant who uses a wheelchair)

Riyadh holds the firm belief that the Ulema are responsible and accountable for not creating inclusive spaces. While some of prevalent persons with disabilities are within the Ummah, they also express difficulty in providing support for certain individuals with disabilities. Sheik Luqman feels that the focus should be on creating accessible and inclusive spaces, as the numbers of people who would use the spaces would then increase.

“You are creating awareness; you know of the one but there may be so many others in the community that you didn’t know of because you are not accommodating them.”

(Sheik Luqman, Ulema)

Imam Saleh identifies financial constraints as a limit to what is done.

“That one person is part of the Ummah. You cannot say you cannot do it or say okay - because there’s one person - we not going to do it but you see why: we always think in terms of money.”

(Imam Saleh, Ulema)

When Moulana Mohamed, a leader with extensive experience in running a Madrasah for Blind and Visually Impaired students, reflects on whether persons with disabilities are fully included within the Ummah, his response was:

“Sadly, no.”

(Moulana Mohamed, Ulema)

He continues:

“You see, when you talk about inclusion another point comes up about support. Our society we are very generous society especially when it comes to Ramadaan people want to give off to charity. So, there are, I would say, relief organisations and organisations that help us to do work but the thing is it is much more than that, it is giving your time, it is giving your concern, it is giving part of your life.”

(Moulana Mohamed, Ulema)

to persons with disabilities within the Ummah, the compartmentalising approach to disability limits possibilities for disability inclusion. The Ulema sees themselves as playing a role in creating awareness of disability within the Ummah. Sheik Luqman says that he could take action by incorporating matters related to disability and disability inclusion Moulana Mohamed recognises that Muslims tend to be charitable by offering financial support but that

this is insufficient for facilitating inclusion. Humaira agrees that there tends to be silence in the Muslim Ummah except as it is seen in terms of deserving charity and sympathy.

“As a Muslim. I feel our inclusivity of people with disabilities is lacking. It’s not something spoken about or explored. A family is usually left figuring out their way, especially when it comes to access to religious spaces and knowledge. The only time I have heard disabilities being discussed in the Muslim community has been through charity events where funds were being collected.”

(Humaira, non-disabled participant)

Moulana Mohamed advocates that this needs to change.

“The mind-set has to change, and the heart also has to change to be more compassionate.”

(Moulana Mohamed, Ulema)

Calls for change to the Ulema’s complacency with regard to disability inclusion are echoed by Mufti Bilal who bemoans the fact that many feel absolved of the responsibility to promote disability inclusion.

“So, they are included in the way that there are people who have dedicated themselves to the needs of the disabled and others busy in their own lives, find solace in the fact that there are some seeing to that, I may not have to and in passing if there is an event that is run by, I do my bit from time to time but (not) in a collective, wholesome, inclusive manner, conscious manner. So, it is seen to be those who have dedicated themselves to it. I think people won’t generally go out of their way to go and enquire about a disabled person and see in which way he or she can make life a bit easier or better for them.”

(Mufti Bilal, Ulema)

Mufti Bilal acknowledges that even he may only do 'his bit from time to time' but is not actively involved in providing inclusive spaces for persons with disabilities. He concedes that Muslims make insufficient effort to include persons with disabilities. Programmes available for persons with disabilities appeared to be few and far-between and involvement is ad hoc. Moulana Mohamed takes issue with the fact that support for disability inclusion is not mainstreamed within the Ummah.

"That is my complaint also, too that I find that our society somebody is handling something - there now that's done over there now."

Sheik Luqman identifies examples of programmes offered by others rather than any examples of his own.

"There is one Masjid actually, I have colleagues who teaches at a Deaf school on Sundays, it , there was project last year or just over a year ago where I know of two Masjids in particular the one for sure, in way of awareness that they would have the interpreter there but then they made it such that the students will only get together Sundays, they meet the Friday morning and then they convey them together to this Masjid because they are all from different areas so they can enjoy it all with their interpreter who they are comfortable with. So yes, a small attempt."

(Sheik Luqman, Ulema)

"So, a colleague of mine he passed away about three years ago, he started this class (for blind adults) more than ten years back."

(Moulana Luqman, Ulema)

Similarly, Imam Saleh identifies certain organisations that provide support for persons with disabilities within the Ummah. He view this as moving towards necessary change.

"I must say that we do have a Madrassa for the Blind and where they can read the Quran in the form of braille but that was only started, I think about ten years ago. But

we as a Muslim Ummah are in South Africa 325 years. But even if it has taken more than 300 years, it's a step in the right direction."

(Imam Saleh, Ulema)

Moulana Mohamed is part of one of the few organisations that provides access to Islamic education for adults who are Blind and Visually Impaired. Part of the work that Moulana Mohamed does is to produce Braille Qurans, which he tries to distribute to all Masjids, thus trying to foster inclusion. His wife has a Madrasah for children who are Blind and Visually Impaired, since these children are still not included in the mainstream Madrasahs.

"There is about five of them. They come to my house because my wife teaches them. That particular group it is a group that is neglected."

(Moulana Mohamed, Ulema)

Like Moulana Mohamed, Moulana Rashid is one of the few Ulema who provides Islamic education for children with disabilities. He described doing this with little knowledge of disability or disability inclusion.

"So, I said, okay, what I initially did was I started with one or two kids whose parents were interested. So, a few parents came, and we tried..... I started a class like this but in my Madrasah structure. So, within the afternoon Madrasah, not separately' I just started a class randomly with knowing nothing. I never studied any special needs, I didn't know what was special needs, I didn't even know what was Cerebral Palsy, I didn't know what was Autism, I didn't know anything, but it was just seeing these children that gave me the strength and the ability. So, for about a year we ran the Madrasah just working on the side, just going like that you know. It was 2005/2006, so it was actually just a class within a Madrasah class. So, it wasn't an organisation. Ja, we didn't have a separate organisation."

(Moulana Rashid, Ulema)

As the need grew they developed a separate facility for children with intellectual disabilities. Moulana Rashid is trying to be inclusive and to create awareness.

“That is what we did. We are inclusive. We did it such that we actually incorporated with the Madrasah with the children, the children used to play with them. Like that we carried on and then eventually the need became greater than we started getting calls for children with learning disabilities. So, we said okay.”

(Moulana Rashid, Ulema)

However, he feels that children with different disabilities and non-disabled children could not be taught in the same space. This led to separation where children with multiple disabilities were separated from both non-disabled children and from children with disabilities.

“Now you know what we didn’t want to create a situation where the two are together in one set up which wasn’t conducive, the physically challenged children and those are academically. If you look at them normal you will think there is nothing wrong with them. So, we put the physically challenged children with them. It was becoming a problem because you know our parents how they are, no I can’t put my child where that type of...you know very sad, unfortunate to say you know. Anyway, so then we divided the two. The one group carried on with the physically challenged which is still running there in Crossly and they go as Ilm Madrasah and that was our actual Madrasah. So, they carried on with that. I said, ‘okay carry on’, and then I branched off and I started with the kids here.”

(Moulana Rashid, Ulema)

Moulana Rashid tried to be inclusive. However, the lack of understanding around disability and parents’ assumptions of and prejudices against disability led to separation and exclusion. The emerging discrimination reflects the poor knowledge and awareness of disability as previously described by participants with disabilities (sub-theme, “The Gaze of Othering’) and

also communicates a hierarchy between disabilities (aligning with descriptions in sub-theme 3,1, 'Inclusion could Create Ease and Belonging').

Imam Saleh is a proactive Imam who is making an ongoing effort to create access and inclusion for persons with disabilities. One of the challenges that Imam Saleh discusses is the way that historic architecture made access difficult.

“Unfortunately, there had been a shortcoming because Mosques in the Western Cape like the Masjid where I am, is 168 years old. The Mosque stands on like a hill and so as we enter - as you come from street level you have to go up quite a few steps but now what about those with disability? So, then we had to accommodate those people, so the top level of the stoep just around the corner from the Mosque, we had to knock in the wall of the stoep and we had to make it accessible for people with wheelchairs.”

“So, from the disability point of view the only thing that we still - we are busy with the renovation of the Mosque and we built new toilets - we need to even make the toilets wheelchair friendly and so those are all the challenges. The other thing in the Masjid that I personally have been looking at but unless there is a request is for somebody in Jumma to do the sign language..... having that hearing aid as an extra facility; it is something that we can look at. There are many things. The unfortunate thing is we are talking about mosques that are over 100 years old but that doesn't stop us from making the necessary amends and alterations.”

(Imam Saleh, Ulema)

He lamented that there were still many Masjids that have a long way to go for the inclusion of persons with disabilities within the Ummah.

“So unfortunately, there are some of the mosques that still need to do that but with one look at the Ummah everyone is not the same.”

(Imam Saleh, Ulema)

Moulana Rashid is proud that his Masjid is accessible to wheelchair users.

“Our Masjid is very accessible; anybody can come there, and we make everyone feel welcome. We are busy with renovations, but a wheelchair access is very accessible there. You can get in with a wheelchair access there are no difficulties in there.”

(Moulana Rashid, Ulema)

He also recognises that it is not accessible to Deaf individuals.

“Look I would love to do that if I get somebody that can teach Sign Language then I would be most willing.”

(Imam Rashid, Ulema)

Furthermore, in acknowledging that more needs to be done for Deaf persons, Mufti Bilal reflects on the difficulty of including Deaf Muslims within the mainstream Madrasahs.

“I fully appreciate and understand that you know what, especially for children with sight impairments it is easier because all you have to do is bring that child in a classroom, that child would have already gone to a Blind school which is offered in the major centres, would have learnt how to read. All you have to do is make sure you have got all the books available and all the rest of it is oral which no disability is for the child.

“But compared to maybe a person hard of hearing it is much more challenging.

“Maybe there we need a specialised facility.”

(Mufti Bilal, Ulema)

While Mufti Bilal attempts to find solutions that best provide support into his sermons and teaching:

“From the Masjid podium.”

(Sheik Luqman – member of the Ulema)

Imam Saleh supports this notion:

"And it's also very important that even as far as even the type of lectures that we give on a Friday, it's important that we must speak on current affairs, those things are very important. So, one needs to base one's Friday sermons on current affairs because you have the perfect, perfect opportunity and you having a ready-made audience."

"But very important - the most powerful platform is the Mimbar (The Masjid Podium)."

(Imam Saleh, Ulema)

Mufti Bilal agrees that the lectures at the Masjid are very important but expresses the need for different strategies of education.

"Of course, that would be the spoken words like the lectures and talks and incidentally I did some talks on Islam and disabilities and so on. I think there are so many platforms available today to create that awareness. You have the spoken word which could be audio format, you could have video clips. You could social media, you could use the printed media, you could use the electronic media. So, the opportunities for spreading that message around are ample and we should try to use every opportunity and every space that is available to us for that."

"Definitely, my view is that the Ulema would most certainly be open to that. They would be quite encouraging of it. There should not be any reason why they should discourage it. There is no reason for it; there is no Islamic basis for discouraging something like this."

(Mufti Bilal, Ulema)

In addition, Moulana Rashid suggests that awareness should be wider than just the talks at the Masjid:

"With the Masjid you have got to have inclusive programme and today you see what happens your major challenge in the Masjid also the people you need to speak to are not there, so the best way to have your programmes is via media. You know you keep on publishing some articles and you know what a little bit of encouragement and you

keep on sending them out, you don't know when it will strike and just at that moment when that person is in that moment and that predicament it strikes, that is where you see the change in attitude."

(Moulana Rashid, Ulema)

This ties in with Dilshad's concern about a lack of presence of information on disability on social media. She sees social media as an important platform for creating awareness which could cascade down to all non-disabled persons within the Ummah.

"Not only mobility wise, I mean if you go on YouTube and you search 'Disabled Muslim' you will find nothing but a few good Khutbahs from Mufti Menk , Omar Suleiman. I think that's the only two people that will talk about disability in there such a lack of knowledge... The reason why aunties and things are people and like not just aunties but anybody they are just..."

(Dilshad, participant with a disability)

Mufti Bilal draws attention to the need for people with decision-making powers to be made aware of the need to create full inclusion for persons with disabilities:

"I think the primary role is obviously education and reaching out to the relevant people to ensure that you know these facilities are created maybe communicates to Masjid committees and so on because ultimately in relation to Masjids the onus is with the Masjid committee to ensure that facilities are created. The Ulema can only advise and guide but they cannot forcibly ensure that the facility is created. But it is ultimately the main role players in this here, would be the Masjid committees. The Chairman and presidents of mosque board and so on. Those are the people who are the key people in all this here."

(Mufti Bilal, Ulema)

Sheik Luqman recognises that the Ulema should be at the forefront of creating inclusion for persons with disabilities.

“You are supposed to be at the forefront in all that is needed in the society so I think if the awareness is there, the awareness in as far as the data is concerned and there are definitely people in each community that have disabilities and the reason why the Imams may not see them is because the Masjids are not disabled-friendly. So, it is about the information first, then the awareness, then definitely it should then set the example for other institutions. Disabled parking bays”

(Sheik Luqman, Ulema)

A significant point for achieving disability inclusion raised by Moulana Mohamed is the need to move away from looking at persons with disabilities with pity.

“A lot of education is required to dispel the misconceptions that people have. We need to educate our people to move away from pity, move away from looking at this person’s disability but what his or her ability and if you look at what his or her ability is you will be shocked.”

“We as Imams, we as people we have too, I would say educate our society and encourage our people that Islam is so beautiful it has a place for you.”

(Moulana Mohamed, Ulema)

The responsibility to change the mindset that Moulana Mohamed refers to should not be the sole responsibility of persons with the disabilities and their families but should be shared by all within the Ummah – persons with disabilities and non-disabled persons. Riyadh claims that the Ulema could ensure that full disability inclusion takes place by creating spaces for physical inclusion and spaces where persons with disabilities are active members in all aspects of life. Riyadh uses the example of playing a leadership role as a teacher of Islamic education to illustrate this. He states:

“My idea of productivity within the communities is something that needs to be looked at. How productive is that person with their illness within that community and how productive can they be, within that, not only the community but within the Ummah, very important to understand that because if we let someone with an impairment

teach Hifz it takes, it takes the understanding of disability to such a higher level that someone with an impairment could actually be the teacher and I think it's very important to understand that we need um not only to include them in and prayers and in their religion but actually to include them in a productive way, it allows them to add value to the community and Ummah."

(Riyadh, participant with a disability)

He asserts that if this were to happen, a powerful message would be sent to the Ummah about persons with disabilities. Hassan explains the role of the Ummah very clearly:

"As a Muslim community - could be a great role model for the rest of the world. That's very important because when you look at the times, the life of the Prophet (SAW), he was representing himself, a good human being - like you can say universal rights, which everyone was accepting. So, for each and every single Muslim, it is a very important point to us that we must know especially in South Africa where we are very small population here. We must know that we are representing our religion. We are representing the Prophet (SAW) and Allah, the Creator that we believe in."

(Hassan, Ulema)

The Ulema acknowledges that they need to offer leadership to ensure that full inclusion of persons with disabilities may be realised. While this acknowledgement is important, the dominant ableist narratives that prevail continue to position persons with disabilities as the 'Other'. This positioning does not recognise persons with disabilities' agency . While it may be that persons with disabilities, as a group, need to continue to use their agency to drive the agenda of full disability inclusion, the Ulema, as the leadership within the Ummah, are key to creating inclusive spaces for persons with disabilities.

5.5 THE CASE OF DISABILITY INCLUSION: MINIMAL INCLUSION, MOSTLY EXCLUSION

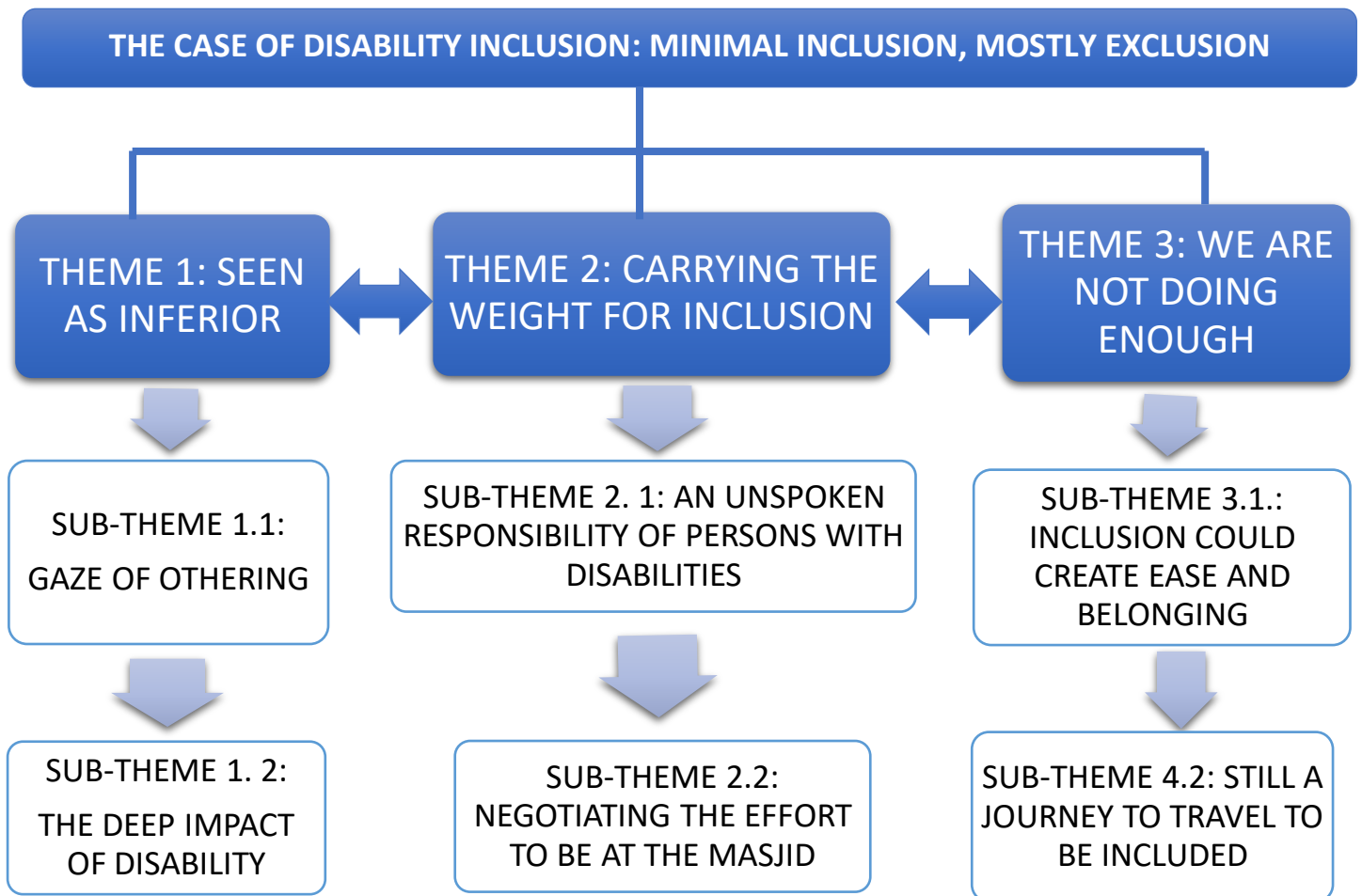


Figure 5. 5: The Case and Themes

The case of disability inclusion in the Muslim Ummah is one of “Minimal inclusion, mostly exclusion”. It is constituted by three themes, namely “Seen as Inferior”, “Carrying the Weight for Inclusion” and “We are not Doing Enough”. These themes describe how disability and disability inclusion is understood, interpreted and enacted within the Ummah and how this contributes to create a situation of minimal inclusion, mostly exclusion.

The Gaze of Othering and the deep Impact of disability contributes to reproducing the normative, ableist discourse demonstrated in Theme 1, “Seen As Inferior” which leads to

experiences of disability exclusion within the Muslim Ummah. When persons with disabilities are “seen as inferior”, they are on the periphery of and not fully included in the Ummah. They are then left to ‘carry the weight of responsibility’ to promote their own inclusion. This responsibility lies with the person with a disability to create their inclusion. This uptake of responsibility is assumed and implicit and is seen particularly in negotiating access to the mosque as “not enough is being done” to create full inclusion for persons with disabilities within the Ummah. Most of the effort is made by persons with disabilities without mutual effort from others in the Ummah and particularly the Ulema. The understanding and interpretation of disability and disability inclusion is fractured and this limits the extent of disability inclusion in the Ummah.

CHAPTER 6: DISCUSSION

6.1 INTRODUCTION

In 1994, South Africa transitioned from legislated apartheid into a democracy which has continued to make significant gains to correct societal injustices and to ensure that all its citizens enjoy the same freedoms and opportunities. However, evidence shows that South Africa remains a very unequal society, with a steadily rising Gini coefficient of 0.70 (Rowe & Moodley, 2013) and the majority of people in South Africa continuing to live in poverty (Nelson Mandela Foundation, 2018). The progress by the South African government in matters related to disability and the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) has also been slow (South African Human Rights Commission, 2016).

Persons with disabilities face various forms of discrimination as they encounter structural inequalities and attitudinal barriers. This discrimination is experienced in different social spheres, including access to health care, employment and education and within the religious and spiritual context (Human Sciences Research Council, 2013 - 2017). While policy development, advocacy, research and individual efforts have focused on mainstreaming disability within the educational, employment, residential, health and community spaces, less attention has been paid to inclusion of persons with disabilities within spiritual and faith-based areas and religious practices (Ault et al., 2013). Religion and spirituality play an important role in the lives of many persons with disabilities, as this is where comfort, strength and inner peace may be found. However, many of these spaces are not fully inclusive of persons with disabilities, as reflected in the findings of this study. Collins and Ault (2010) state the while persons with disabilities may place importance on religious affiliations, at times, some churches maintain or even erect barriers that may discourage and exclude participation.

This chapter discusses how disability inclusion was framed by participants in the study through addressing 2 critical areas that emerged from the findings, as depicted in figure 6.1 below:

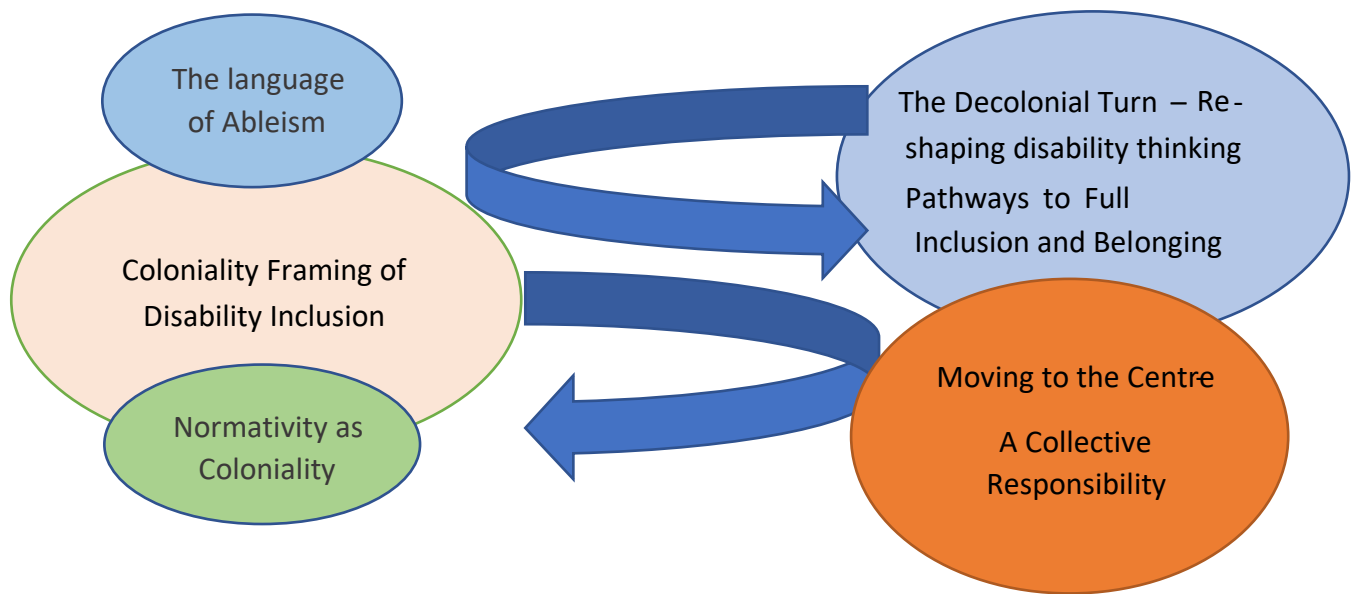


Figure 6. 1: 2 Critical areas of discussion

Firstly, the normative and ableist discourses framing disability are identified as examples of coloniality. The divergent ways in which disability is interpreted by both persons with disabilities and non-disabled persons influences the way disability inclusion occurs. It appears that an ableist discourse of disability dominated and created a hierarchy where normativity was valued. The influence of this coloniality on the way disability inclusion is enacted within the Ummah is described, foregrounding how this contributes to experiences of exclusion by both the person with a disability and the rest of the Ummah. Secondly, a possible pathway to full inclusion and belonging through making the de-colonial turn by re-shaping discourses of disability within the Ummah, is discussed, suggesting that it is a collective responsibility within the Ummah to play a meaningful role in countering the slow progress of disability inclusion identified in this study.

6.2 COLONIALITY THROUGH THE NORMATIVE AND ABLEIST FRAMING OF DISABILITY INCLUSION

While Muslims, both with and without disabilities, experienced discrimination within the broader South African context, the findings show that this experience of segregation for Muslims with disabilities, continues to be felt within the Ummah. This is especially evident in the ways that the language of Ableism (see 6.2.1 below) prevails. Anderson (2006) explains that barriers leading to discrimination when participating in various faith-based communities is a concern (Anderson, 2006). This was apparent in the many instances where persons with

disabilities both Muslims and non-Muslims, globally indicated that they would like to participate in faith-based communities but experienced barriers in these spaces (Anderson, 2006).

One of the main findings of this study is that the manner in which disability and disability inclusion is interpreted impacts on how disability inclusion occurs within various spaces and places within the Ummah. Although persons with disabilities and non-disabled persons in this study vary in their explanations of disability, the ableist discourse dominates the explanations.

6.2.1 The Language of Ableism

Ableism, like other "isms" such as racism and sexism, describes discrimination towards a social group, in this case persons with disabilities (Friedman & Owen, 2017; Nario-Redmond, Kemerling, & Silverman, 2019). Ableism is premised on the assumption that people with disabilities are inferior to non-disabled persons, based on the limitations of their bodily abilities; for this reason, they are devalued and discriminated against. This prejudice is informed by beliefs about a person's capacity to perform or function in a way that meets a normative standard. The ableist discourse of disability, as Garland-Thomson (2014) explains, strives for the ideal of sameness and 'abnormal' is seen as the 'other'. Ableism is frequently seen as being indicative of the oppression of and discrimination against persons with disabilities (D'Souza, 2016). The critique of coloniality as explained in chapter 3 (page 44) (Hull, 2021), highlights that persons with disabilities are often invisibilised and that this occurs through dominant discourses, such as ableism. This appears to be consistent with the findings of this study, since invisibilising of disability, persons with disabilities and disability inclusion within the Ummah occurs.

The findings show that the majority of the Ulema's interpretations of disability, focus on the person's inability. This is demonstrated through the use of terms like '*imperfection*', '*hampered in their functioning*' or '*deficiency*' (5.2 THEME 1: "SEEN AS INFERIOR" pg. 76). In their interpretations of disability, the dominant explanation by the participants lies in the differentiation between 'normal' and 'abnormal', 'normal' being non-disabled persons and 'abnormal' being persons with disabilities. In

explaining their understanding of disability, non-disabled persons' interpretation of disability is limited to expressions of deficit. Such internalised sets of assumptions about persons with disabilities reflect little knowledge of diverse disabilities and this appeared to influence the way non-disabled persons engaged with persons with disabilities. What this ableist language appears to do is to reinforce the status quo of normality as perceived by the majority (non-disabled persons), so that disability is measured against this norm. This being the "universal truth", of how persons with disabilities are viewed by non-disabled persons. Similarly, in a study carried out by Cologon (2016), it was identified that the concept of 'normal' is used to define disability, with disability being understood as being 'not normal', 'different' or 'abnormal'. A symptom of ableism is then seen as a 'promise' that ablement (ablebodiedness) is something that is within reach and should be striven for by all (Campbell, 2019). Ableism thus reinforces the image of perfection and excludes all that does not meet this perceived 'perfection.' The disabled body is thus seen as an object of fear and pity, in contrast the 'able' body which is perceived as a being a precondition for the pursuit of happiness (Jordan, 2013).

While a definition of 'normal', what qualifies a person as 'normal' and what the image of such a person is, is elusive and even problematic, (Swinton, 2012, p. 179) reminds us that the only 'truth is that the real norm for human beings, on a genetic level, is difference'. Foucault 1997 in Cologon, 2016) argues that the group that is the strongest establishes its own rules about what can be known and how it can be known (Cologon, 2016, p. 12).

The ableist discourse is aligned to the medicalisation of the body, where the main focus is on finding a solution to the impaired body. From a medical model perspective, the person with a disability is considered deficient and, hopefully, alterable (Andrews et al., 2020; Runswick-Cole, 2008). This view has long held negative implications for persons with disabilities (Goering, 2015; Scullion, 2010; Swain & French, 2000). Furthermore, Anastasiou and Kauffman (2013) assert that persons with disabilities are seen as victims of a tragedy by non-disabled persons. This ableist language is so embedded in ways of thinking and being that persons with disabilities also tend to embrace these ways of thinking, judging themselves using this binary discourse. In the current study, persons with disabilities, although being

quite clear about their expectations of disability inclusion, are also accepting of the ableist discourse of 'normal' / 'abnormal' (

5.2 THEME 1: "SEEN AS INFERIOR" pg. 76). This might reflect a tension between the desire for disability inclusion and the ableist discourse where participants with disabilities demonstrate acceptance of the language of ableism, measuring themselves against the majority within society.

This narrative of exclusion is commonplace and mostly evident in the ways in which persons with disabilities self - efface to make others feel comfortable in order to keep peace (5.3 THEME 2: CARRYING THE WEIGHT FOR INCLUSION pg. 91) In an attempt to explain this consent to the ableist discourse (Meekosha & Shuttleworth, 2009). They endorse Fanon's (1970) interpretation that 'central to maintaining colonised peoples in a subordinate role has been the process whereby hegemonic ideologies of the dominant groups are transferred and internalised by the dominated' (Meekosha & Shuttleworth, 2009). Internalised oppression, particular to the disability experience (Meekosha & Shuttleworth, 2009), is evident in the narrative of acceptance of disability exclusion in persons with disabilities in their desire and actions to be accepted and to achieve this through assimilating into the broader non-disabled community (5.3.1 SUB-THEME 2.1: THE UNSPOKEN RESPONSIBILITY OF PERSONS WITH DISABILITY TO CREATE INCLUSION pg. 93-95). This places emotional strain on the person with a disability, as power remains with non-disabled persons. This disempowers not only the person with a disability but influences their families too. Since there was little to no challenge to the assumed power of non-disabled persons or their responsibility to shift their assumptions and discomforts with disability, an opportunity was missed. This missed opportunity was evident in the ways that existing ableist discourses continue to dismiss or invisibilise disability and persons with disabilities.

6.2.2 Normativity as Coloniality

'As modern subjects, we breathe coloniality all the time and everyday' (Maldonado-Torres, 2007).

Coloniality survives colonialism and is maintained through many aspects of our modern experience, including through discourses of ableism (Maldonado-Torres, 2007). Ableism may be viewed as a form of colonial thinking in that it categorises representations of groupings of people according to the normative standard of 'perfect' and other. This comparative framework of othering has similarities with colonialisation where, 'the overarching purpose of racial classification and racial hierarchisation was to construct a system of social differentiation, a distinction in social category between those who could define others and those who would always be subjects and objects of definition' (Martinot nd:3 as cited in Ndlovu-Gatsheni, 2014). Grech (2015) states that when the coloniser started to encounter the other, 'it had to construct the other racially, culturally, bodily and spiritually'. The system of colonisation emphasised white superiority, positioning people of different races as other and inferior in relation to whiteness, where the white body signifies perfection. In the ableist discourse this presence of colonial thinking is evident, in that, whatever goes against the 'normal', 'perfect' body' is considered inferior.

In relation to the current study, participants identified as Indian or Coloured with disabilities, who measure against white superiority are considered inferior, both because of their race and their disability. In this study, there has been noticeable silence around race and disability, in that the influence of race was not explicitly identified. This is an area that could be pursued in future research in order to further explore the intersections of race. The perspective of coloniality appears to have been adopted by the Ummah in South Africa, seemingly with little awareness of its presence and pervasiveness. This way of thinking is apparent in the theme, 'We are not doing Enough' when, in their explanation of creating inclusion, non-disabled participants refer to an intention to make this life better for persons with disabilities (5.4. THEME 3: WE ARE NOT DOING ENOUGH pg. 107) by making 'them feel accepted' (pg. 114) and 'putting persons with disabilities in able-bodied situations' (5.4.1. SUB-THEME 3.1.: INCLUSION COULD CREATE EASE AND BELONGING pg. 109). Despite these good intentions, non-disabled persons inadvertently appear to paternalistically position themselves as 'superior' to persons with disabilities. It appears that this patronising way of taking responsibility for improving the situation for persons with disabilities, highlights their

impairments and reflects possible beliefs that persons with disabilities have no, or little, agency.

The medical model supports similar deficit discourses which emphasises the body–mind defects of people with disabilities, placing a negative emphasis on disability and persons with disabilities (Gebhardt et al., 2022; Loja et al., 2013). This pattern of thinking leaves non-disabled persons in control over most matters related to persons with disabilities within the Ummah, reducing opportunities for persons with disabilities to exercise their agency, instead, framing persons with disabilities as the beneficiaries of help, recipients of charity (Michael Oliver, 1990) . Loja et al. (2013) argue that this familiar situation is based on a historical legacy of disability where persons with disabilities are reduced to ‘objects of benefaction’ (Loja et al., 2013) thus entrenching the benevolent side of ableism (Loja et al., 2013; Nario-Redmond et al., 2019) with non-disabled persons being benevolent and ‘helping’ them.

This perception is apparent in the contradiction at play in the findings of this study, where non-disabled participants articulate a desire to create an inclusive space but adopt a patronising approach to contributing to empowering persons with disabilities (5.4.1. SUB-THEME 3.1.: INCLUSION COULD CREATE EASE AND BELONGING pg. 109). Reynolds (2012) notes that often non-disabled persons in their well-intentioned endeavours to assist people with disabilities actually marginalise them. Such marginalisation occurs even when participants with disabilities attempt to use their voices individually to effect changes, as a compromise to full inclusion, in their particular spaces. The dominant belief that persons with disabilities have little or no political voice or influence has yet to be challenged and explored fully (Howell, Lorenzo, & Sompeta-Gcaza, 2019). In this compartmentalisation of persons with disabilities and non-disabled persons, a divide is created and, with this divide, comes a power imbalance. Since decision-making power appears to rest in the hands of non-disabled persons, this power imbalance favours non-disabled persons and occurs in various forms and in many different spaces.

The power imbalance is particularly evident in the way non-disabled persons, especially those individuals in leadership positions, engage with persons with disabilities. Correspondingly,

colonialism prescribes how disability is to be engaged with and at times 'treated' (Grech, 2015). Santos (2007) recognises that an imbalance of power inevitably produces social exclusion.

Coloniality of Power displays itself where some aspects of people's identities are depicted as superior to others, premised on the belief that a superior degree of humanity is attributable to the person having these aspects. Race is one such aspect of identity. It is suggested that that the 'lighter one's skin is, the closer to being more human one is and vice versa' (Maldonado-Torres, 2007). In a similar vein, applying the ableist discourse, it is proposed that the person with a disability is judged against what is considered 'normal'. Non-disabled persons, viewed as normal, are considered superior to the inferior person with a disability. Coloniality maintains such divides between persons with disabilities and non-disabled persons through the ways in which non-disabled persons perceive persons with disabilities as the other (Reynolds, 2012). Loja et al. (2013) assert that the notion of normality, which is rooted in the medical model, is at the core of the othering process which views disability as a 'physical, moral, emotional, mental and spiritual deficit'. This divide between 'Us', non-disabled persons and 'Them', persons with disabilities, contributes to dismissing the case for disability inclusion by invisibilising disability (Reynolds, 2012).

Within the Ummah, othering continues, unconsciously excluding persons with disabilities, even when they advocate for their inclusion. This has led to many instances where disability inclusion is dismissed as unimportant. One way this othering is manifested in this study is through the Gaze of Othering (5.2.1 SUB-THEME 1.1.: THE GAZE OF OTHERING pg. 81). The gaze which is a visual act displays modes of domination, power and control and has the ability to categorise people. This gaze has the power to generate feelings of shame and to assert the superiority of the one doing the gazing (Al-Qahtani, 2021). There are many forms of the gaze viz the colonial Gaze, the racial gaze, feminine gaze, the photographic gaze, to name a few (Al-Qahtani, 2021; Baderoon, 2014, 2019).

The effect of the ableist discourse and coloniality of power on the experience of disability inclusion in the Ummah is that non-disabled persons tend to prescribe how change happens for persons with disabilities. The findings of this study show that some of the factors

contributing to this othering are a lack of knowledge, insight and thought given to the way someone with a disability can, for example, fulfil an obligatory Islamic requirement such as their Salaah (daily prayers) in communal spaces. Persons with disabilities' agency remains unacknowledged, conceivably leaving them feeling excluded and dehumanised. This is evident from the experiences of participants with disabilities reflected in 5.2.1 SUB-THEME 1.1.: THE GAZE OF OTHERING, pg. 81; 5.3 THEME 2: CARRYING THE WEIGHT FOR INCLUSION, pg. 91; 5.3.1 SUB-THEME 2.1: THE UNSPOKEN RESPONSIBILITY OF PERSONS WITH DISABILITY TO CREATE INCLUSION, pg. 93). With their voices muted, persons with disabilities are perceived as 'foreigners' within their own society (Garland-Thomson, 2014). This also reflects coloniality of knowledge since one group feels that they know better than others and imposes this knowledge, advancing the notion that 'Others Cannot Think' (Maldonado-Torres, 2007). This is evident from the experience of the participant using a wheelchair who was informed by a non-disabled member of the Masjid that his wheelchair wheels would dirty the carpet, without first finding out the Islamic injunction on this matter (5.3 THEME 2: CARRYING THE WEIGHT FOR INCLUSION, pg. 91).

The person was diminished to the position of a bystander in a matter that was deeply significant to him, a position that Ndlovu-Gatsheni recognises as coloniality limiting agency in African people (2014). The coloniser, such as non-disabled persons in some instances, assumes the power of knowledge, imposing their thoughts and beliefs on to the colonised, persons with disabilities, thus giving themselves authority and creating the false belief that they are superior to the one being colonised (Ndlovu-Gatsheni, 2014). Thus, the power rests in the hands of a few.

This power imbalance imposed on persons with disabilities is evident from the findings where the person with a disability was silenced into acquiescing to the powers that be in the Masjid space, workspace or public space. The findings show that often this leads to the person with a disability retreating into the background, (5.3.1 SUB-THEME 2.1: THE UNSPOKEN RESPONSIBILITY OF PERSONS WITH DISABILITY TO CREATE INCLUSION, pg. 95) or making an extra effort to 'fit in' to make others feel comfortable (5.3.1 SUB-THEME 2.1: THE UNSPOKEN RESPONSIBILITY OF PERSONS WITH DISABILITY TO CREATE INCLUSION, pg. 93), often at a

personal sacrifice (5.4.1. SUB-THEME 3.1.: INCLUSION COULD CREATE EASE AND BELONGING, pg. 113), silencing their agency and activism.

This invisibilising contributes to dehumanising people through denying persons with disabilities within the Ummah their full rights as practicing Muslims who are equal to everyone else in the Ummah. This entrenches the experience of not belonging for persons with disabilities within the Ummah. The Capabilities Approach with its focus on building social connections and analysing the extent to which the social, cultural and religious dynamics of the context contribute to expanding or impeding choices available to individuals within a community is useful in identifying the dehumanising and invisibilising of persons with disabilities within the Ummah. Highlighting that choices and freedoms of persons with disabilities are extremely limited (Trani et al., 2009).

The process of dehumanising is not only experienced by the person with a disability in isolation but by the entire family in some form or other. This is evident in claims that '*Our family is incapacitated*' within the findings (5.2.2 SUB-THEME 1.2. THE DEEP IMPACT OF DISABILITY, pg. 88). Swinton (2012) states that it is not enough that human beings are simply included in communities, they also need to feel a sense of belonging. He advocates that when this sense of belonging does not happen, full inclusion will never be realised (Swinton, 2012). The places and spaces where dehumanising, invisibilising and dismissing happen are diverse and some, such as the Masjid, carry profound meaning for people with disabilities. The Masjid plays a pivotal role in the life of practising Muslims as a place of prayer, where they go to be one with their Creator; the Masjid is known as the House of Allah (beit Allah). Since this is a place where Allah alone is worshipped and remembered (Abdel-Hady, 2010), it is not only restricted to being a place of worship, a location for performing rituals or a social and political dimension of the Muslim community. Instead, it serves as a symbol of belonging and identity (Abdel-Hady, 2010) that is a central institution to the formation of Muslim identity and community and to the functioning of the Ummah.

Since 'the worship of God has always been the cornerstone of every religion, places of worship occupy an important position in the daily life of all religious communities' (Abdel-Hady, 2010). This space that holds deep meaning for a Muslim (Abdel-Hady, 2010) and where spiritual

connection with one's Creator happens is censored and becomes an unwelcoming space for someone with a disability. The Coloniality of Being experienced by persons with disabilities within the Ummah is likened to experiences of apartheid by some participants (5.2.1 SUB-THEME 1.1.: THE GAZE OF OTHERING, pg. 81; 5.3.2 SUB-THEME 2.2: NEGOTIATING THE EFFORT TO BE AT THE MASJID, pg. 97). The person with a disability is pushed to the periphery, relegated to the margins of the Ummah. This state of incompleteness (Ndlovu-Gatsheni, 2014) of persons with disabilities is pervasive across different levels of the Ummah. The humanness of people is dehumanised in that their connection with their Creator is disregarded through a sense of not belonging and as the Gaze of Othering is played out in this space (5.3.2 SUB-THEME 2.2: NEGOTIATING THE EFFORT TO BE AT THE MASJID, pg. 97, 98-103). However, according to Islam, the Masjid, as the 'House of Allah', is said to belong to all within the Ummah since, once a Masjid is built, it does not belong to any human, the owner of the Masjid is God alone. The Masjid does not require membership, every Muslim is equally entitled to be part of this space. This means that the expression 'House of God' is not only figuratively true, but also legally true under Islamic law (Alfaruqi & Alfaruqi, 1986 as cited in Abdel-Hady, 2010).

The Masjid may be viewed as a microcosm of the situation within the Ummah since it is the nucleus that determines the characteristics of a Muslim society (Abdel-Hady, 2010). It appears that the dehumanising not only occurs for adults with disabilities, but also for children during their Islamic education. For persons with disabilities, lack of access to Islamic education begins in childhood, creating an exclusion from an early age for a person with a disability (5.2.1 SUB-THEME 1.1.: THE GAZE OF OTHERING, pg. 81 -81 for the implications of this lack of access to adequate Islamic education). Islamic education is a pre-requisite for all within the Ummah from an early age, as seeking knowledge through education is one of the duties placed on every Muslim. Lack of access to this education and knowledge is thus a barrier that restricts their practice as Muslims. Education is viewed as a method by which human beings are trained and prepared in an intensive manner to do their Creator's bidding and to help establish Allah's decree in this life, with the intention that it will lead to a reward in the hereafter, or the afterlife (Hassan, 1988 as cited in Nor, 2017; Erfan & Valie, 1995 as cited in Tamuri, Ismail, & Jasmi, 2012).

The findings of the current study further show that the experience of being dehumanised filters into the social, work and public spaces frequented by persons with disabilities through the pervasive invisibilising of intellect, of knowledge and of person. These experiences are reflected through the Gaze of Othering, where persons with disabilities are excluded from social interactions, from family gatherings and from public spaces (5.2.1 SUB-THEME 1.1.: THE GAZE OF OTHERING, pp. 81-81). This places persons with disabilities on the margins within the Ummah. Loja et al. (2013) state that ‘the (non-disabled) gaze is the medium through which ableism invalidates the impaired body and, at the same time, sustains its own authenticity’.

As these discourses of ableism persist and perpetuate narratives of exclusion, non-disabled persons retain the power and opportunity to ‘other’ and dehumanise persons with disabilities. There is a need to interrupt this tension, to challenge the normalising, ableist way of thinking. To facilitate a shift, challenging prevalent ways of thinking about disability and ableist discourses in the ummah are needed.

To do so is to contribute to decolonising and de-imperialising the way non-disabled persons view disability by challenging existing, long-held assumptions about disability inclusion. This reflects a need to work with deep identity and power issues related to persons with disabilities and their place within the Ummah. In this study, the intersectional relationship between disability and coloniality (Grech, 2015) was revealed. The study unveiled the intersectionality of religion and disability did not fully explore how aspects of identity such as gender, race and class intersect with disability. Exploring these concepts further will allow for further pluriversal ideas to be uncovered.

6.3 EMBRACING THE DECOLONIAL TURN THROUGH RE-SHAPING DISABILITY

THINKING - PATHWAYS TO FULL INCLUSION AND BELONGING

The decolonial turn is a concept introduced by W.E.B. Du Bois and has been put forward by Maldonado-Torres (2007) as a way in which to address a de-colonisation process, as it re-centres the focus on persons and matters usually relegated to the periphery. A decolonial turn makes a shift in knowledge use in the Ummah, making ‘the invisible visible’ (Maldonado-

Torres, 2007). Presently, there is a divide between persons with disabilities and non-disabled persons in the Ummah. However, rendering the existing divide visible may contribute to bringing into focus the consequences of ableist, colonial discourses and may challenge the status quo. It may also reveal the pervasive, subtle presence of ableist discrimination in its many forms, highlighting where and how this presents. Through this, existing power imbalances may become more apparent and may yield possible options for change and for guiding possibilities for belonging and full inclusion.

Applying a decolonial turn to reshape the way disability and disability inclusion is conceptualised in the Muslim Ummah is integral to promoting full disability inclusion and belonging. Making the de-colonial turn can help challenge the universality of the ableist narrative within the Ummah. Re-shaping thinking about disability and disability inclusion through making a decolonial turn involves making a shift from a colonial attitude towards a decolonial attitude (Maldonado-Torres, 2007) which embraces new ways of understanding disability. This may be achieved through processes that involve naming the unconscious exclusion that has silently prevailed, identifying the barriers to full inclusion and allowing for opportunities for full inclusion and belonging to be advanced.

This proposed shift is depicted in figure 6.2 below:

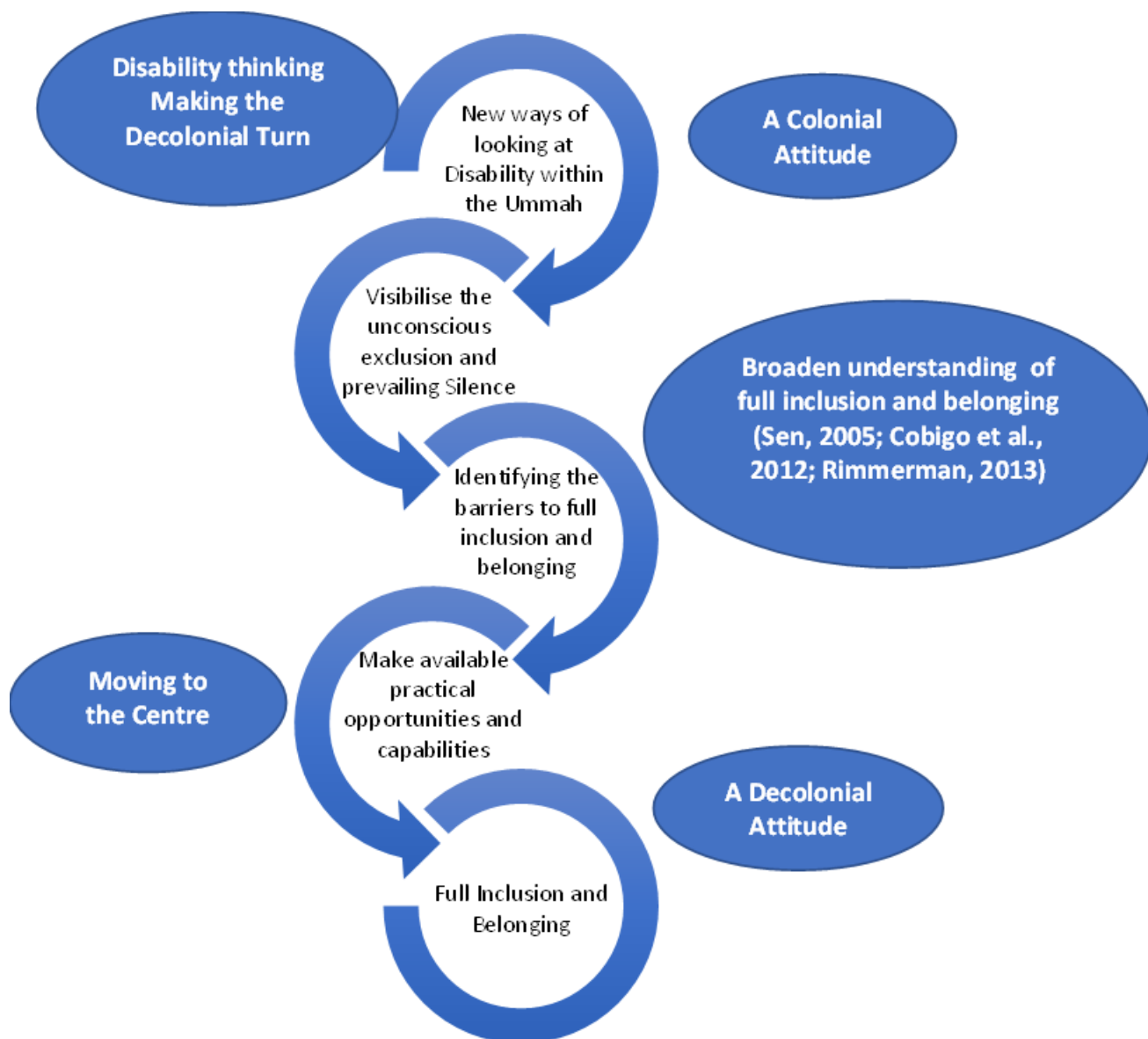


Figure 6. 2: The pathway to full inclusion and belonging by making the decolonial turn

The portrayal of disability and persons with disabilities within the Ummah as described in the theme, “Seen as Inferior” is not without consequence. The discussion thus far has explained the profound ways in which an ableist, colonial discourse emerges as an example of the Coloniality of Being of persons with disabilities. The consequence of this is manifested in the unconscious exclusion of persons with disabilities and the pervasive silence around this exclusion within the Ummah. Making the decolonial turn and embracing a decolonial attitude may facilitate pathways to full inclusion and belonging by reshaping disability thinking through new ways of looking at disability within the Ummah.

This silence on disability and disability inclusion is not only the silencing of the voices of the persons with disabilities, it is evident in many other ways. These include silence from the leadership, especially during their sermons at the podiums in Masjids, the silence that exists in mainstreaming Islamic education for persons with disabilities and the silence within the Muslim media around disability (5.4.2 SUB-THEME 3.2: 'STILL A JOURNEY TO TRAVEL TO BE INCLUDED', pg. 115). Another silence that has been neglected, is the way that the intersectionality between gender and disability is demonstrated in the exclusion experienced (5.2.1 SUB-THEME 1.1.: THE GAZE OF OTHERING, pg. 84)

Intersectionality captures the way that various axes of identity, for example, gender, race, ability and sexuality interrelate on multiple levels and often concurrently, creating a system of oppression and multiple forms of discrimination (Dutta, 2015). In this study, this is evident in women's experiences of accessing places of worship. Women with disabilities are further disadvantaged, especially with regard to the physical accessibility of the Masjid for those with mobility impairments. This prejudice appears to be systemic and should be made visible in order to start a deliberate move to actualise the elusive full inclusion in the Ummah. A systematic dismantling of exclusion within the Ummah requires a process to decolonise or de-imperialise the way exclusion has occurred to date.

Re-shaping of disability thinking in the Ummah would visibilise the unconscious exclusion and the accompanying silence and would enable the relevant stakeholders to identify the elements that may have contributed to not achieving full inclusion and to realise the critical importance of providing persons with disabilities access to capabilities or opportunities which result in achieved functioning for the person with a disability, ultimately leading to a sense of belonging. The principle of belonging to a social network within which one receives and contributes support (Cobigo et al., 2012) alludes to belonging within a community, in this case, the Ummah. It means playing a meaningful role within the Ummah and not only being there symbolically. The understanding is that once the relevant mechanisms are in place for full inclusion, persons with disabilities will have the choice to access or inhabit whatever spaces and places they wish in the Ummah. Individuals will also have the option not to

participate or seek inclusion and may prefer privacy and autonomy (Cobigo et al., 2012; Rimmerman, 2013).

6.3.1 Moving to the Centre – A Collective Responsibility towards Full Inclusion and Belonging

This pathway towards full inclusion and belonging is informed by the principles of the capability approach and understanding of disability inclusion according to Cobigo et al. (2012) and Rimmerman (2013) principles of social inclusion (see Figure 2 for illustration). The processes of decolonising disability inclusion provide a broad lens from which to view the landscape of full inclusion and belonging, calling for collective action to expedite this inclusion and belonging.

Persons with disabilities need to move from the margins, which they currently occupy, to the centre of the Ummah, to be on the same plane as non-disabled persons. The processes of rendering disability visible in the decolonial turn should simultaneously involve interventions at the levels of power, knowledge and being (Maldonado-Torres, 2007), with collective, collaborative responsibility, of both persons with disabilities and non-disabled persons in the Ummah, for the processes of change.

The findings indicate that the participants with disabilities identify the Ulema as key role players in this de-imperialisation process since there has been silence from the Ulema in elevating disability matters within the Ummah (5.4.2 SUB-THEME 3.2: 'STILL A JOURNEY TO TRAVEL TO BE INCLUDED', pg. 115-117). However, although the Ulema may have an important role to play in the decolonisation process, they are not the only drivers needed in this process. Collaboration between the leadership and persons with disabilities is necessary to assist in making a decolonial turn. Persons with disabilities have a significant role to play in the process. The collective process also needs to seek out the voices of the women with Islamic knowledge (Muallima) within the Ummah to further address this exclusion within the Ummah. The collective responsibility lies with both the 'coloniser' and the 'colonised', with each person or group having a different role to play in the decolonisation process. The idea of a collective process allows for sharing power rather than continuing with the creation of

full inclusion through those who have always held the power. The discourse around decolonisation takes the form of an invitation to dialogue, a desire for exchange and is not seen as an imposition by the coloniser (non-disabled) over the colonised (persons with disabilities) (Maldonado-Torres, 2007). There should be reciprocity in the process. An element to be cognisant of is the issue of hierarchy that manifests within the interpretation of disability by some participants with disabilities; this may contribute to the slow progress of disability inclusion (

5.2 THEME 1: "SEEN AS INFERIOR", pg. 76 -77).

The decolonisation approach would also allow the Ummah to begin to shift their thinking of inclusion as a narrow, deficit, ableist, colonial lens to a broader decolonial view of disability and disability inclusion and belonging. The dominant colonial knowledge could be challenged and re-shaped. A decolonial attitude to disability by non-disabled persons is necessary for the de-colonisation process to be implemented. An ideological shift from the ableist, colonial way of interpreting disability is necessary, as this impacts on disability inclusion. The voices of the persons with disabilities should be heard given credence and importance in mapping a way forward towards full inclusion and belonging. The principle, promulgated by Cobigo et al. (2012), of being recognised as a competent individual and trusted to perform social roles in the community speaks to this point. Persons with disabilities are the experts and understand explicitly what interventions need to happen and how (5.4.2 SUB-THEME 3.2: 'STILL A JOURNEY TO TRAVEL TO BE INCLUDED', pg. 115). However, even once this move to the centre is achieved, caution should be taken to ensure that non-disabled persons do not continue to prescribe how inclusion for persons with disabilities happens.

While this pathway is relevant to this study, it may also be relevant for other faith-based communities in assessing the level of inclusion/ exclusion within their spaces. The pathway might be used in re-shaping disability thinking within these faith-based communities, leading to more inclusive spaces for persons with disabilities.

CHAPTER SEVEN: SUMMARY, RECOMMENDATIONS AND CONCLUSION

‘This Ummah is like one body, if one part is hurt then the whole body suffers’

Prophet Mohammed (PBUH)

7.1 INTRODUCTION

This chapter brings together the critical elements of the study, discussing its limitations and making recommendations to facilitate a pathway to full inclusion and belonging for persons with disabilities within the Ummah. These include policy implementation, curriculum change and future research.

The research question is: **‘How is Disability Inclusion interpreted, experienced and enacted by persons within the Muslim Ummah in South Africa?’** It aims to gain insight into how disability inclusion is enacted within the Muslim Ummah in South Africa.

The conceptual framework underpinning the study is Amartya Sen’s Capability Framework. Together with Cobigo *et al.*’s (2012) principles of social inclusion, the framework has allowed the researcher, to view full inclusion and belonging through a broad lens. This framework speaks to what the participants with disabilities have voiced around the ideal of full inclusion and belonging

The research objectives explore the interpretation and experience of disability inclusion for persons with disabilities within the Muslim Ummah, for Ulema within the Muslim Ummah, for families of persons with disabilities and for non-disabled persons within the Muslim Ummah.

7.2 SUMMARY OF THE STUDY

The interest in this study emanated from conversations with persons with disabilities around the many challenges experienced within the Ummah. Religious expression is enmeshed in the lives of many as they make meaning of the world; and their experiences within these spaces have a significant impact on their lives (Imhoff, 2017). The purpose of the study is to engage with persons with disabilities and non-disabled persons in the Ummah to understand how

disability inclusion is interpreted and experienced in the Ummah, in an attempt to create dialogue around disability and how it is played out in the Ummah.

Literature reviewed indicates that there is a gap in research in this area, especially in South Africa, and a need was identified to address this in order to elevate an important area of concern within the Ummah.

In this study, an interpretative qualitative research design with an intrinsic case study method (Creswell, 2007; Orb et al., 2001), is employed to explore and examine how disability inclusion is interpreted and experienced by people within the Muslim Ummah in South Africa. Four key group of persons within the Ummah are part of the study as they are either directly impacted by disability inclusion or play an important role in ensuring disability inclusion. These include seven persons with disabilities, five family members of persons with disabilities, six people from the Ulema and three non-disabled persons from the Ummah. All 21 participants are interviewed for the study. All participants are 18 and older.

Data generation sources include in-depth, face-to-face interviews with the participants and analysing three Muslim publications. The interviews allow an opportunity for detailed exploration with each of the participants.

An interpretative qualitative method of enquiry is appropriate for the study as the views of the participants are crucial in answering the research question. The voices of the participants provide an insight into the way disability inclusion is interpreted and experienced within the Muslim Ummah in South Africa.

The Muslim publications are analysed to gain an understanding of the Muslim media's focus on issues of disability inclusion in their write-ups. The data collected from the interviews I transcribed verbatim and analysed to look for patterns in the data. These are coded accordingly.

Three themes emerge from the analysis was: “Seen as Inferior”, “Carrying the Weight for Inclusion” and “We are not Doing Enough” with two sub-themes under each theme. The Sub-‘Seen as Inferior’ and the two sub-themes, ‘The Gaze of Othering’ and ‘The Deep Impact of Disability’ bring into focus how persons with disabilities are viewed as being inferior within the Ummah and this is displayed through the gaze. The sub-themes also highlight the impact of this gaze on persons with disabilities and their families. The theme “Carrying the Weight For Inclusion” highlights the responsibility taken on by persons with disabilities to be accepted and included within the Ummah; this is demonstrated through the two sub-themes ‘The Unspoken Responsibility of Negotiating Persons with Disabilities’ and “Negotiating the Effort to be at the Masjid’. These sub-themes further explain the emotional and physical impact of this responsibility.

At present, the inclusion occurs in silos for a few in the Ummah. Most often, it is persons with disabilities who make the effort to be present in an Ummah that is not fully inclusive or welcoming of persons with disabilities. Persons with disabilities often have to take on the responsibility of making non-disabled persons feel comfortable about their disabilities so that persons with disabilities will feel accepted and included within the Ummah. This involves huge emotional, psychological and physical effort on the part of the persons with disabilities. The implication of this is that non-disabled persons are exonerated from the responsibility of accepting the exclusion that is present in the Ummah, happy that persons with disabilities are seen to be present in these spaces.

The ableist, normative, colonial discourse that emerges from the findings has deep implications for persons with disabilities and their place within the Ummah. This narrative impacts negatively on disability inclusion in the Ummah, highlighting that disability inclusion is still very much in its infancy. The relationship between disability and spirituality is an important one. However, many persons with disabilities experience a problematic relationship with faith communities and no positive association has developed between persons with disabilities and their faith communities (Calder, 2012). The conceptual framework create a space for transformative engagement around disability inclusion within the Islamic discourse and assists the researcher to create a pathway to guide the Ummah

towards making a shift from the colonial, ableist, normative narrative and attitude to making the decolonial turn to full inclusion and belonging of persons with disabilities in the Ummah.

By calling into question the ideologies of privileging normalcy, the church can play an important role in disrupting the ableist, normative, colonial narrative (Calder, 2012; Reynolds, 2012). This can be done by re-shaping disability thinking through the generation of new ways of looking at disability within the Ummah. It can help identify the elements that may have contributed to not achieving full inclusion and to understand what full inclusion and belonging should encompass and how they should be enacted. This decolonisation process will allow for the interpretation of full inclusion and belonging to be re-shaped and embedded within the Ummah, as a way of achieving the desired situation of full inclusion and belonging for persons with disabilities and for their families.

The exclusion, which has been termed unconscious exclusion, prevails because of the silence that surrounds it and is evident in many different places and spaces within the Ummah. Persons with disabilities are key in challenging this exclusion and silence and play a critical role in actioning the pathway to full inclusion and belonging and making the decolonial turn. Unless the voices of persons with disabilities are heard in the process of generating new ways of looking at disability in re-shaping of disability thinking, this pathway will once again follow the route of non-disabled persons 'doing' for persons of disabilities. Persons with disabilities themselves have a critical role to play in ensuring that the power balance that is present in the Ummah between persons with disabilities and non-disabilities is not allowed to endure.

An influence of coloniality, which needs further interrogation, is the adoption of the ableist, colonial discourse by many participants with disabilities. The impact of this may be a contributing factor that has slowed the move to full inclusion and belonging. The hierarchical element within disabilities that emerges in the study also needs to be part of the broader discussion around what has contributed to this slow move to full inclusion. Furthermore, families of persons with disabilities are also crucial in this process as they have a wealth of knowledge and their contribution is very valuable.

7.3 LIMITATIONS

As this study is an exploratory one, only certain categories of persons with disabilities were selected to participate in order to manage the scope of the study. As explained earlier, while including persons with neurocognitive or psychiatric impairments may have enriched the study, it would have also add further demands to the way the study was managed, which was beyond the capacity of the researcher to implement.

Another limitation was the short time period available for reviewing the publications. Had the time limit been extended, more editions of the publications could have been reviewed.

7.4 RECOMMENDATIONS

The researcher is aware that her work is only just the beginning; that she, together with the persons with disabilities in the Ummah, and other role-players, have a huge task ahead to create practical opportunities to elevate the voices of persons with disabilities so that the unconscious exclusion is no longer silent. The silence has to be broken, to be shattered. Therefore, the recommendations will be presented in two sections:

7.4.1 TEACHING, LEARNING AND PRACTICE

A systemic change is necessary within the Ummah and, while all individuals in the Ummah, those with disabilities as well as non-disabled persons, are important role players in ensuring that the decolonialisation process is successful, the Ulema are significant drivers within this group.

The Ulema bear the responsibility to ensure that the Hadith quoted at the beginning of this chapter (saying of the Prophet Mohammed) (PBUH), is realised for everyone, but particularly with respect to this study and what the findings have elicited. The findings should be the forerunners in implementing the pathway to full inclusion and belonging. They have also been identified by the participants as key to re-shaping disability thinking. The generating of new ways of looking at disability and the implementation of the pathway may take many forms. Public talks held by the Ulema, whether at the Friday sermons, public gatherings, or online

platforms, should all be seen as practical opportunities to re-shape disability thinking. The print media and community radio stations offer other opportunities that should be used to the maximum.

The Ulema are respected theologians within the Ummah and the knowledge shared by them is, most often, held in high esteem. The knowledge shared at these platforms cascades not only to their specific congregations but far beyond. Inclusion of disability as a topic in the curricula of the teaching and learning areas where training of the Ulema occurs is imperative for the reshaping of notions of disability. This would become embedded in the thinking of the teachers from the onset. In including educational content around disability within the curricula, institutions could impact future generations of religious leaders and their congregations (Anderson, 2006). Teachers who are responsible for providing Islamic education to children would become aware that children with disabilities are part of the teaching and learning cohort and would be equipped through knowledge creation to act on this.

The teaching should be carried through to adult education as well. The Ulema in these institutions of teaching and learning, often head or are part of either a Masjid or an Islamic non-governmental institution and may continue to start Madrasahs of their own; the knowledge instilled in their training would become part of the way they managed their own institutions in respect of inclusion of persons with disabilities. Theological education prepares clergy to lead congregations and the knowledge gained around disability could make a systemic impact (Anderson, 2006). A toolkit needs to be developed to support the introduction of disability inclusion training in the curricula.

Non-disabled persons in the Ummah, besides being ordinary members of the Ummah, may also be board members of a Masjid or manage organisations that employ persons with disabilities and would all benefit from this re-shaping through the practical implementation of the pathway to full inclusion and belonging.

Architects who are responsible for either building new Masjids and other facilities or renovating existing structures all have a responsibility to ensure that they adequately meet the requirements of creating full inclusion of persons with disabilities.

People within the Ummah involved in all sectors and forms of media, both mainstream media and faith-specific publications are encouraged to highlight disability in their publications, thus contributing to re-shaping disability thinking. A regular column in these publications can be dedicated to highlighting disability matters with both persons with disabilities as well as non-disabled persons contributing.

It is anticipated that there are some individuals within the Ummah who are open to taking this pathway forward and others who are resistant, as this is a new area, unfamiliar to the majority of the Ummah. The insights into the pathway to full inclusion and belonging can be used as a tool within the Masjid spaces by re-shaping the thinking around disability in the Ummah, challenging the ableist, colonial discourse. In applying the CA, through the focus on capabilities seen, as real freedoms, any potential barriers to full inclusion are corrected (Robeyns & Byskov, 2020). This includes workshops, teaching and learning within the theological spaces and mainstream teaching institutions in making a decolonial turn.

The processes of decolonising disability inclusion provide a broad lens from which to view the landscape of full inclusion and belonging, calling for collective action to expedite this inclusion and belonging. Persons with disabilities are central in engaging with and actioning this pathway framework.

Academic institutions, through their Disability Studies and Religious Studies programmes would all benefit from including disability and religion and spirituality in their curricula, thus generating new ways of looking at disability.

7.4.2. RECOMMENDATIONS FOR FUTURE RESEARCH

There is a dearth of literature in this area and future researchers should be encouraged to venture into these areas of research as discussed below.

1. The implementation of the pathway to full inclusion and belonging, will provide rich data in the validation of this tool of empowerment in re-shaping disability and creating disability inclusion within the Ummah and will guide changes that need to be made to the pathway to benefit further practice.
2. The research design adopted in this study limited ongoing research engagement with persons with disabilities in this study. Future research and practice should therefore shift in designs and methodology to include more participatory elements. Participatory action research is recommended, where persons with disabilities are co-researchers in the research process.
3. The scope of the current study has not included children and persons with neurocognitive or psychiatric impairments; further research is needed in these areas to explore the impact of the dominance of the ableist, normative, colonial discourse in the Ummah for these groups of individuals.
4. The intersectionality between gender and disability and further exclusion experienced by women with disabilities within the Ummah is noted in the study and is an area that requires further research. This should include the voices of women in the Ulema. The current study has not focused on these.
5. Further research is needed around the intersectionality between race and disability in the Ummah. This is an area not emphasised in the conversations with the participants and an area that needs to be explored further.
6. The dominance of the ableist, normative, colonial discourse within the study highlights how entrenched this discourse has become with theologians and members of the Ummah. This needs further research, not only in the Muslim Ummah but across other faith-based organisations as well how this.

7.6 CONCLUSION

This chapter summarises the methodology and theoretical framework applied in this study. Furthermore, it offers suggestions for moving forward towards achieving full inclusion and belonging for persons with disabilities in the Ummah.

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APPENDIX A: INFORMATION LETTER

Dear Participant

My name is Nafisa Mayat and I am a PhD student studying at the University of Cape Town. The title of my study is: A CASE STUDY EXPLORING DISABILITY INCLUSION WITHIN THE MUSLIM UMMAH IN SOUTH AFRICA.

The purpose of the study is to understand how disability inclusion is enacted within the Muslim Ummah in South Africa. It will focus on the experiences of disability inclusion of persons with disabilities within the Muslim Ummah. This study has the potential of creating dialogue around issues of disability, thus creating new knowledge within the Muslim Ummah that will lead to opportunities for inclusion and participation of persons with disabilities within the Muslim Ummah.

You have been invited to participate in this study as your experience around disability inclusion within the Muslim Ummah will add great value to this study. The participants that have been selected are persons with disabilities within the Muslim Ummah, the Ulema within the respective communities, families of persons with disabilities and non-disabled persons from within the community. In order to gather data for this study, at least two in-depth interviews will be held with each group of participants to discuss their understanding and experience of disability inclusion within the Muslim Ummah. The interview will take place at a setting of your choice. You will not be reimbursed for participating in the study but where necessary, transport and meal costs will be covered.

The interview will be conducted in English and will be in a format that is accessible to all participants. Sign Language Interpreters will be provided where required.

Participants will also be asked to take photographs of those images that speak to their experience of disability inclusion. They will be provided with a camera to capture these images (photographs) and where necessary training in taking photographs will be provided. They will be provided with a separate consent form to obtain consent for the use of the images (photographs) captured as part of the study (See Appendix E).

Your participation is completely voluntary and you are free to decline. You are also free to withdraw from the study at any time without the need to provide an explanation. Your confidentiality will be protected and your name will not be used in the research documents.

The researcher will ensure that no harm comes to you and if, at any time, there is any psychological distress experienced when talking about your experience, the necessary support will be provided for you and you will be referred for psychological support if you so wish. At the initial interview, a list of names of psychologists will be provided should you require their services. There will not be any risks to the participants who may agree to participate in the study. Participants will not be paid for being part of the study.

There might be some concepts that are new and unfamiliar to you and these will be explained for more clarity

The documents will be stored in a secure place and only the researcher and the supervisors will have access to the information. The research findings will be sent back to you for verification before publishing any of the data.

I would also like to seek your permission to record the interviews.

The Information letter and Informed Consent Form will be sent via email and a hard copy will be provided at the initial interview. You will have one week to consider whether you would like to participate in this study. This will give you time to raise any questions or ask for clarification if required.

Should have any further questions, you can contact:

Nafisa Mayat at 0827868976

Email: nafisa.mayat@uct.ac.za

My supervisor: Professor SL Amosun – (021) 406 6992

Email: seyi.amosun@uct.ac.za

Any questions on the ethics of this research can be directed to the faculty of Health and Rehabilitations Sciences, Human Research Ethics Committee, University of Cape Town.

Contact Details:

Chairperson: Professor Marc Blockman

Room: E52.24

Old Main Building, Groote Schuur Hospital

Tel: (021) 406 6492 Fax: (021) 406 6411

Yours sincerely

Nafisa Mayat

(Please find the Informed Consent Form below)

APPENDIX B: DEMOGRAPHIC DETAILS

| | |
|---|--|
| Name | |
| Age | |
| Disability | |
| Race | |
| Gender | |
| Marital Status | |
| Position in the Family | |
| Highest level of education | |
| Occupation | |
| No. of years living in current community | |

APPENDIX C: INFORMED CONSENT FORM FOR MOSQUE DOCUMENTS

Name of representative of the management of the mosque:

_____ have read (or had read to me by _____) the Information Sheet. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no dire consequences for me. I have been guaranteed that confidentiality will be maintained during this study. I understand that my identity will only be revealed in an instance where any criminal activity has been uncovered on my path and the researcher is obliged to report it to the relevant authorities. I understand that the documents will be stored in a secure place and only the researcher and the supervisors will have access to the information. The research findings will be sent back to me for verification before publishing the data.

I understand that the mosque documents provided will be treated with utmost confidentiality and that the names and identity of the mosque concerned will not be revealed.

All information about any individual with a disability discussed in any of the documents will be kept confidential.

Signed:

Participant

Date and Place

Researcher

Date and Place

Witness (if necessary)

Date and Place

APPENXID D: INFORMED CONSENT FORM FOR INTERVIEWS

Institution and name of participant:

I _____ have read (or had read to me by _____) the Information Sheet. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no dire consequences for me. I have been guaranteed that confidentiality will be maintained during this study. I understand that my identity will only be revealed in an instance where any criminal activity has been uncovered on my path and the researcher is obliged to report it to the relevant authorities. I understand that the documents will be stored in a secure place and only the researcher and the supervisors will have access to the information. The research findings will be sent back to me for verification before publishing the data.

New and unfamiliar concepts that I might not understand have been explained to me. Should I experience psychological distress the researcher will refer me to an appropriate mental health practitioner.

At least two interviews will be carried out. I am aware that a Sign Language Interpreter will be provided where required. I understand that I will not be remunerated for participating in the study but my transport costs and meals will be covered if the interview is held at a venue away from my place of residence.

The Information letter and Informed Consent Form was sent to me via email and a hard copy will be provided at the initial interview. I had one week to consider whether I would like to participate in this study, to allow for clarification on any issues.

Signed:

Participant

Date and Place

Researcher

Date and Place

Witness (if necessary)

Date and Place

APEENDIX E: INTERVIEW SCHEDULE

Interview Schedule

The opening question to all participants that will lead them into the broader discussion will be:

What is your understanding of disability?

Interview with the person with a disability

To explore the understanding and experiences of disability inclusion for people with disabilities within the Muslim Ummah

- What do you understand by disability inclusion?
- What is your understanding of an Ummah?
- How have you experienced disability inclusion within the Ummah generally?
- How have you experienced disability inclusion within the specific religious environment that you are part of?

Interview with the Ulema

To explore the understanding and experiences of disability inclusion of people with disabilities for the Ulema within the Muslim ummah • What is your understanding of disability inclusion?

- What is your understanding of an Ummah?
- Do you feel that Muslims with disabilities are included within the Ummah? Explain further.
- How do you see the Masjid playing a role in creating disability inclusion?

Interview with a family member of the person with a disability

To explore the understanding and experiences of disability inclusion for families of people with disabilities within the Muslim Ummah

- What is your understanding of disability inclusion?

- What is your understanding of an Ummah?
- What is your experience of disability inclusion, in particular within the Muslim Ummah?
- Tell me more about how it has impacted on you, being a family member of someone with a disability? Can you give me some examples?

Interview with a non-disabled person

To explore the understanding and experiences of disability inclusion of people with disabilities for non-disabled persons within the Muslim ummah

- Do you know someone with a disability?
- What is your understanding of an Ummah?
- Tell me more about your understanding of disability inclusion?
- How do you think your specific religious environment is inclusive of people with disabilities? Explain further

**APPENDIX F: INFORMED CONSENT FORM FOR STUDY PARTICIPANTS
REQUIRED TO TAKE PHOTOGRAPHIC IMAGES**

Institution and name of participant:

I _____ have read (or had read to me by _____) the Information Sheet. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no dire consequences for me. I have been guaranteed that confidentiality will be maintained during this study. I understand that my identity will only be revealed in an instance where any criminal activity has been uncovered on my path and the researcher is obliged to report it to the relevant authorities. I understand that the documents will be stored in a secure place and only the researcher and the supervisors will have access to the information. The research findings will be sent back to me for verification before publishing any of the data.

I understand that no photographic images will be used without my consent. Permission will be sought from me should the photographic images need to be used for academic publications, research reports and all distinguishing features will be blocked out of the photographic images. I understand that I have the right to refuse the use of the images that have been taken by me.

I understand that I will need to explain the ethical process of taking pictures to the individuals whose photographic images I will be taking. Permission must be sought before taking the photograph images and the individual has the right to refuse for his/her image to be taken. I will need to explain that the photographic images will be taken for research focusing on disability inclusion within the Muslim community and that the images will not be used for any other purposes other than for academic purposes. I will explain to the individual whose image is taken that no image will be used without his/her consent.

I will answer all queries and concerns raised by the individuals truthfully and honestly.

Signed:

Participant

Date and Place

Researcher

Date and Place

Witness (if necessary)

Date and Place

APPENDIX G

Informed Consent Form for individuals whose photographic images are being taken Institution and name of participant:

I _____ have read (or had read to me by _____) the Information Sheet. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no dire consequences for me. I have been guaranteed that confidentiality will be maintained during this study. I understand that my identity will only be revealed in an instance where any criminal activity has been uncovered on my path and the researcher is obliged to report it to the relevant authorities. I understand that the documents will be stored in a secure place and only the researcher and the supervisors will have access to the information. The research findings will be sent back to me for verification before publishing any of the data.

I understand that that the photographic images being taken will be for research focusing on disability inclusion within the Muslim community.

I understand that no photographic images will be used without my consent. Permission will be sought from me should the photographic images need to be used for academic publications, research reports and all distinguishing features will be blocked out of the images (photographs). I understand that I have the right to refuse the use of the images that have been taken of me.

Signed:

Participant

Date and Place

Researcher

Date and Place

Witness (if necessary)

Date and Place

APPENDIX H



Figure H. 1: Entrance leading into the University of Cape Town prayer facility



Figure H. 2: First entrance into the University of Cape Town prayer facility



Figure H. 3: Second entrance into the University of Cape Town prayer facility

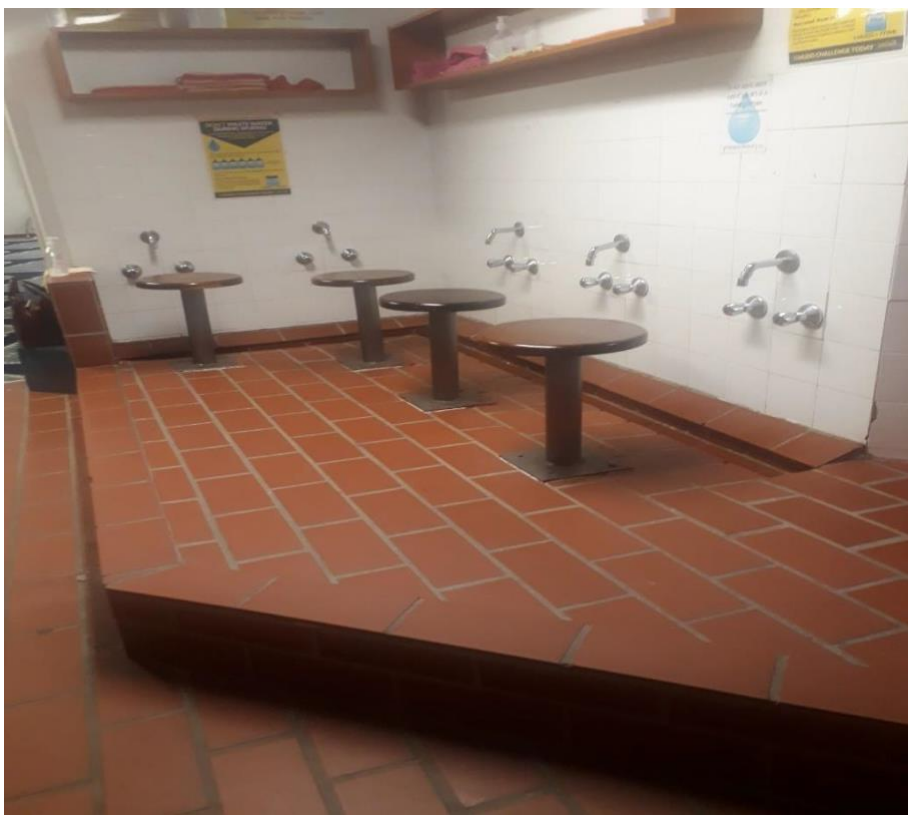


Figure H. 4: Ablution facility